

Open Research Online

The Open University's repository of research publications and other research outputs

Volunteers in End-of-Life Care: How is their Role Constructed?

Thesis

How to cite:

France, Rachel (2020). Volunteers in End-of-Life Care: How is their Role Constructed? PhD thesis The Open University.

For guidance on citations see [FAQs](#).

© 2019 The Author



<https://creativecommons.org/licenses/by-nc-nd/4.0/>

Version: Version of Record

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.21954/ou.ro.0001123c>

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's data [policy](#) on reuse of materials please consult the policies page.

oro.open.ac.uk

Volunteers in End-of-Life Care: How is their Role Constructed?

Rachel FRANCE

(BA (Hons), BSc (Hons), MSc)

Thesis presented for the degree of Doctorate in Philosophy

Faculty of Wellbeing, Education and Language Studies

The Open University

August 2019

[deliberately left blank]

Abstract

This thesis explores the everyday world of hospice volunteers in two UK adult hospices using an ethnographic approach combining participant observation, 'extended conversations' with staff and analysis of hospice documents. I aimed to uncover how the hospice volunteer role was constructed drawing on data from volunteers in three care settings: day hospice, inpatient and bereavement. The thesis employs Hockey's (1990) conceptualisation of the hospice 'journey' as a 'biological continuum' – from living to dying, to death and (for bereaved relatives) back to life – to illuminate how the construction of the volunteer role depends on the proximity to the life-death boundary of the patient/client in these settings.

Following Ganesh and McAllum's (2012) proposition that 'volunteer' and 'professional' are constructed in tension with each other, I argue that death and dying is professionalised terrain in which, volunteers as *un*-professional and thus potentially 'threatening', are problematic. Drawing on Douglas (1966/2002), I suggest that volunteers may be 'matter out of place' (p.203) and that volunteering could be incommensurable with the medical model.

The thesis distinguishes volunteers in 'general' roles (serving meals and drinks, washing up and socialising with patients) from those offering skills for which professional training is required, mostly complementary therapists and care assistants. It shows how the roles of the former are 'bounded' to keep them away from death and dying, while the latter are the subject of more direct strategies to treat them as either anomalous or ambiguous.

Relegating volunteers, particularly those in the inpatient unit, to the periphery of hospice care regardless of the skills they offer contrasts with hospice ideology that volunteers are an integral part of the non-hierarchical multi-disciplinary team. This thesis has helped to reveal the extent to which this is the case.

Acknowledgements

I would like to express my gratitude to my supervisors, Dr Carol Komaromy and Professor Jan Draper, who stuck by me throughout what turned out to be a very long and, at times, bumpy, journey, providing invaluable support, inspiration and encouragement. Also, I acknowledge the additional support of Dr Lindsay O'Dell who helped with sorting out the extra time I needed when my PhD journey was so abruptly interrupted by serious illness. I would, of course, like to thank the volunteers, staff and patients at the two hospices I researched in. Without their good grace, humour and patience, this thesis would not have been possible. I also acknowledge the support of my fellow PhD students, particularly Janet Underwood, without whom I would probably have thrown in the towel. I say thank you to Denise Bradey, Halley Stewart Library, St Christopher's Hospice, for access to original documents. Last, but definitely not least, I acknowledge the support of my very long-suffering husband, Colin, who managed to keep me going through it all. Thank you, all.

Table of Contents

Abstract.....	1
Acknowledgements	2
Chapter 1. Introduction.....	5
1.1 The origins of the thesis.....	5
1.2 What do I mean by 'role'? The development of a theoretical context	6
1.3 Palliative and end-of-life care	8
1.4 The hospice context.....	9
1.5 The volunteering context.....	9
1.6 Volunteers in hospices.....	11
1.7 The aims of the thesis	12
1.8 Outline of the thesis.....	12
Chapter 2. The hospice movement and volunteers: origins and development	15
2.1 The changing context of death and dying.....	15
2.2 The modern hospice movement: a new approach	17
2.3 The contemporary hospice 'movement': bureaucratisation and professionalisation	24
2.4 Volunteering in the UK.....	28
2.5 Understanding the hospice volunteer role	36
2.6 Focus on the staff-volunteer boundary	43
2.7 Boundaries: their role in the management of death	46
2.8 Disconnect between ideology and practice: dramaturgy.....	49
2.9 Summary	51
Chapter 3. Methodology and methods	53
3.1 A social constructionist methodology.....	54
3.2 An ethnographic approach	55
3.3 Research context.....	59
3.4 Fieldwork sites, settings and volunteers.....	64
3.5 Fieldwork methods	69
3.6 Data analysis	79
3.7 Summary	81
Chapter 4. Hospice space: the sequestration of death.....	82
4.1 Lefebvre and the social production of space	83
4.2 Outside spaces: sequestering death and dying	84
4.3 Reception areas: 'protecting' the life-death boundary	86
4.4 Day hospice spaces as 'living' spaces.....	90
4.5 Inpatient Unit: Boundaries/forbidden territories.....	96
4.6 Summary	108
Chapter 5. Day hospice – the performance of 'living'	109
5.1 Hospitality	110
5.2 Preparing the performance.....	111
5.3 Patient confidentiality: the script	117
5.4 Pre-session briefings	119

5.5	'Show time'	124
5.6	Promoting 'living' by resisting 'dying'	134
5.7	Summary	139
Chapter 6.	Inpatient unit volunteers: isolating boundaries.....	140
6.1	Hospitality through meal structure	140
6.2	Vignette: a supper shift with Katy	142
6.3	Hospitality and the production of 'living'	146
6.4	Isolation through boundaries	151
6.5	Producing the living-dying boundary – focus on patient rooms	159
6.6	Summary	163
Chapter 7.	'Professional' volunteers: 'matter out of place'	165
7.1	Anomalies: inpatient unit care assistant volunteers	166
7.2	Excluding them from the team	167
7.3	'Downgrading' volunteers	173
7.4	Sending them home	179
7.5	View from the other side: why involve volunteers?.....	180
7.6	Ambiguities: day hospice professional volunteers	181
7.7	Summary	185
Chapter 8.	Bereavement team volunteers: return to 'living'	187
8.1	Bereavement models.....	188
8.2	Preparing the performance: the script.....	189
8.3	Coffee Time: maintaining the life-death boundary	191
8.4	Telephone Support: ensuring 'living'	197
8.5	Death is for experts	202
8.6	Volunteers: we can't do without them	206
8.7	Summary	207
Chapter 9.	Discussion and conclusions.....	209
9.1	Summary of the research process and findings	209
9.2	The professionalisation of the life-death boundary	212
9.3	Is the hospice volunteer liminal?.....	213
9.4	Discursive strategies	216
9.5	Is volunteering 'work'?	217
9.6	Methodological reflections.....	218
9.7	This study's contribution to knowledge, strengths and limitations, and suggestions for further research.....	221
9.8	Implications for practice	224
9.9	Overall conclusions.....	226
References	227
Appendix A	Figure illustrating the life-death-life continuum	245
Appendix B	Patient and family information.....	246
Appendix C	Information for participants	247
Appendix D	Participant consent form	249
Appendix E	Hospice documents accessed during fieldwork	250
Appendix F	Flora House Ground Floor Plan.....	252
Appendix G	Flora House Lower Ground Floor.....	253
Appendix H	Daisy Hospice Floor Plan.....	254
Appendix I	Findings by research question and data chapter	255

Chapter 1. Introduction

This thesis is about the role of volunteers in hospices who have direct contact with patients and families. It presents an ethnographic study in which I immersed myself in the volunteers' world in two UK hospices for adults. It investigates how the volunteer role is 'matter out of place' in the professionalised territory of death and dying. Contrasting the role in different settings – day hospice, inpatient unit and bereavement care – provided insight into how the role depended on the construction of living and dying in the hospice.

This chapter sets the scene by explaining the origins of the research, including the development of the theoretical approach. It also provides a background to palliative care in the UK, hospices and volunteers, before setting out the aims and structure of the thesis.

1.1 The origins of the thesis

My interest in volunteering began when I spent about a year as a volunteer in a National Health Service (NHS) mental health hospital, initially on a ward for people with dementia, and then on a ward for older women with serious mental illness. The roles on both wards were totally undefined and I was left largely to my own devices (it was 1999). On the dementia ward, I volunteered during a weekday morning. I helped to feed patients and undertook social activities with patients who had some verbal skills, chatted with visiting relatives and helped to take patients to a weekly chapel service. I altered the day of the week on which I volunteered deliberately to coincide with this as I felt it was something I could do to be 'useful'. On the second ward, where I volunteered after patients had finished their evening meal, I spent time socialising with the patients, such as chatting, reading to them, and playing cards (they taught me a game they were particularly fond of). A great deal of the time I felt uncomfortable and out of place. I found that I had to 'negotiate' a role. This involved discussing with staff things I could do and also gradually developing relationships with individual patients. After I had volunteered for a time on the second ward, I was unable to attend for a couple of weeks. On my next visit another volunteer had started. I realised that she was doing very similar things to me, and I wondered how she knew what to do and whether there was something about 'volunteer' which led us both to do these things. That is, did 'volunteer' have a social meaning?

More recently I worked as a researcher on a project about volunteers who have direct contact with patients and families in end-of-life care (Burbeck¹, Low, et al., 2014; Burbeck, Candy, Low, & Rees, 2014b; Burbeck et al., 2015; Candy, France, Low, & Sampson, 2015). This brought back memories of my earlier experiences, in particular the feeling of being 'out of place' and of negotiating the role. One part of this project was to undertake a synthesis of existing studies providing qualitative data about the volunteer role. I was able to set up this piece of work myself and, based on my previous experiences, I wondered whether it would be possible to discover how the volunteer role was 'understood' by those involved (see Burbeck, Candy, et al., 2014). By this I meant how did those involved (volunteers, patients, relatives and healthcare professionals) conceive the role of volunteer. I was interested in finding the 'shape' of this role, what it is and what is left behind when the individual is taken out of it. In other words, what does 'volunteer' mean? This led to my starting point for this thesis of 'volunteer' as a social construction.

1.2 What do I mean by 'role'? The development of a theoretical context

As I explain in Chapter 2, a social constructionist viewpoint 'focuses on the way in which individuals construct and make sense of the world around them (...) [since] what people perceive as real *is real* in its consequences' (Howarth, 2007, p. 212). Taylor (2005) provides an explanation of 'volunteer' based in the organisation of labour relations:

'(...) 'the volunteer' and the symbolic meanings assigned to unpaid work are a product of the social relationships and organisation of labour in particular historical periods (...). It was the introduction of paid workers in formal employment relations in these organisations that led to the creation of the volunteer' (p. 123 and p. 124).

Therefore, the construct 'role' relies for its meaning on reference to, and relationship with, other roles. In the case of the hospice volunteer, this is to the role(s) of paid staff. However, this definition of 'volunteer' – depending on the context – also hinges on another construct, that of 'work'. As Grint (1991) says, 'Work is socially constructed ... there are aspects of social activities which we construe as work and this embodies social organizations' (Grint, 1991, p. 12). These constructs are further situated within the broader concept of the institution:

¹Earlier publications are under my maiden name, Rachel Burbeck

Institutionalisation occurs whenever there is a reciprocal typification of habitualized [sic] actions by types of actors... every institution has a body of transmitted recipe knowledge, that is, knowledge that supplies the institutionally appropriate rules of conduct. It [ie the recipe knowledge] defines and constructs the roles to be played in the context of the institutions in question. (Berger & Luckmann, 1966/1991, p. 72 and p. 83)

Institutional roles are therefore socially constructed; they create social reality within the institution for those involved, and this was the focus of my research. However, Arhne (1994) distinguishes an institution from an organisation, seeing an institution as the *ideas* about which social activities are organised and the organisation as a '*materialised institution*' (p. 4, my emphasis). I approached the hospice as both of these: as an institution largely through the role of its ideology on the volunteer role (although, as I describe in Chapter 2 the hospice movement initially aimed to *de*-institutionalise care for dying people), but also as an organisation through its material practices. I discuss hospice ideology in Chapter 2 and introduce hospice materiality in Chapter 4.

Both an organisation and the roles within it can be delineated from other organisations and roles by the boundaries from which they are constituted. Ardener (1981) draws on, among others, Mary Douglas who was interested in how boundaries work to avoid chaos (for example, Douglas, 1966/2002) to highlight the tensions which arise from boundaries:

In studying the way people pattern their perceptions, attention has been especially drawn to the significance of the perimeters of the categories [my emphasis] that we make in order to codify and confront the worlds we create, in which we then live, and how we cope with some of the problems that arise from the existence of these boundaries (p. 11).

The construct of boundaries therefore formed the basis of my theoretical approach to my data, underpinned by the work of Mary Douglas which I describe in Chapter 2.

Having set out the origins of my research, in the next three sections I describe the background of the study: palliative care, and the hospice and volunteering contexts.

1.3 Palliative and end-of-life care

The terms palliative care and end-of-life care are often used interchangeably and with some confusion (Kellehear, 2005). Palliative care can be defined as care for those with life-limiting or life-threatening disease which aims to improve the quality of life of patients and their families, including physical, psychosocial and spiritual aspects. The National Council for Palliative Care (NCPC)² defined it as:

The active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments (NCPC, (n.d), p. 1).

Palliative care has been associated with care for people with cancer (Kellehear, 2005), although patients with other diagnoses have similar needs (Seymour, 2012). In the UK the term end-of-life care is being used in government policy to refer to care of older people, particularly those with dementia (Seymour, 2012), and was used in the End-of-Life Care Strategy for England (DOH, 2008) where it was defined as care which:

Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support (National Council for Palliative Care (2006), in DOH (2008), p. 47).

Since the publication of this strategy the term end-of-life care has largely replaced palliative care (Seymour & Cassel, 2017). In this thesis I therefore use the term end-of-life care to reflect this common usage in the UK. However, when referring to existing literature, I use the term adopted by the relevant author(s).

² The NCPC merged with Hospice UK in 2017.

1.4 The hospice context

Etkind et al. (2017) estimate that by 2040 population growth in England and Wales will result in an increase in the number of people requiring palliative care of between 25% and 47%. Many deaths are likely to follow a period of long-term illness requiring support at the end of life, such as cancer, dementia, heart disease, stroke, chronic respiratory disease and neurological disease (DOH, 2008). The demand for hospice care is therefore likely to rise considerably.

In the UK there are 466 hospice organisations providing 1,500 services (NCPC, 2013). Most of these are run outside statutory services, although they receive around a third of their funding from the NHS, with the remainder from voluntary donations and active fund raising. About 20% of palliative care beds in England, Wales and Northern Ireland are in NHS facilities (NCPC, 2013).

Just under 6% of all deaths in England in 2017 occurred in hospices, although this figure does not include people who died at home but received care from a hospice-at-home service. The figure accounts for 18% of deaths from cancer but fewer than 1% of deaths where dementia was a factor (calculated from Office for National Statistics figures (ONS, 2018)). While a majority of hospice patients have a diagnosis of cancer (NCPC, 2013), this is changing. For example, while over 6% of hospice inpatients in 1999-2000 had non-cancer diagnoses this rose to 11% in 2011-12 (NCPC, 2013). Compared with the number of people who die in hospices, more people access hospice services in the last months or years of life, with over 360,000 people using services annually (Payne, Preston, Turner, & Rolls, 2013). It is estimated that caring for patients in palliative care services reduces health service costs (notably hospital costs) (data for England) (Hatzia Andreu, Archontakis, & Daly, 2008).

1.5 The volunteering context

The voluntary sector has played a large part in providing a range of services in the UK, including the setting up of schools and hospitals in Victorian England and the many charity-run helplines providing advice and a listening ear today, such as those run by Parkinson's UK, the British Heart Foundation and Macmillan Cancer Support. More recently volunteering was given priority by the UK government 'Big Society' initiative originally set out in the Conservative party manifesto in 2010 (Conservative Party, 2010), although it has been criticised by other political parties and trades unions as a way of disguising cuts in services (for example, Watt, 2010). The 2015

Conservative Party manifesto pledged that organisations with more than 250 employees would be obligated to allow employees' three days' paid leave specifically for volunteering (Conservative Party, 2015), although the policy is still to be introduced (for example, <https://skillmakers.co.uk/community/volunteering/what-is-employer-supported-volunteering> accessed 8 July 2019).

Volunteering can also be considered a public health intervention in its own right (Jenkinson et al., 2013). It is associated with a range of health benefits, including increased longevity; improved ability to carry out activities of daily living; better health coping mechanisms; adoption of healthy lifestyles; and improved quality of life, social support, interaction, and self-esteem (Casiday, Kinsman, Fisher, & Bamba, 2008).

There are an estimated three million volunteers in health and social care in England where they are considered an important part of the workforce, particularly in terms of improving patients' experience of care (Naylor, Mundle, Weeks, & Buck, 2013). Most volunteers are involved with voluntary sector organisations rather than statutory services, although in some NHS organisations volunteer numbers add 10% to overall workforce numbers (Naylor et al., 2013).

A volunteer can be defined by three key characteristics (UN, 1999):

- The activity for which he or she is volunteering their time should not be undertaken primarily for financial reward, although the reimbursement of expenses and some token payment may be allowed.
- The activity should be undertaken voluntarily, according to an individual's own free-will.
- The activity should be of benefit to someone other than the volunteer or to society at large.

There is some debate about whether the definition of volunteering should reference a volunteer's intention, ranging from aiming specifically to help others to wanting simply to produce a 'public good' (Wilson, 2000). For the purposes of this thesis a volunteer is defined as the first two criteria above, regardless of motivation or benefit to a third party (although the literature on volunteers generally assumes that they are of benefit (Eliasoph, 2011)).

Based on Kelemen, Mangan, and Moffat's (2017) typology of volunteering, my focus was mainly on volunteers who volunteered for altruistic reasons, although some of the volunteers I met could

also be defined by this typology as volunteering for instrumental reasons (for example, volunteering to gain experience for a future career).

It should be noted that some organisations involving volunteers prefer to avoid the term 'work' or 'use' in relation to volunteers (Volunteer Canada, 2001) and I follow this convention in this thesis. I use the term 'staff' to refer only to paid employees.

1.6 Volunteers in hospices

Volunteering for hospice organisations is one of the most common settings for volunteer support in health and care settings in England (Naylor et al., 2013). There is a long association between volunteers and the hospice movement with volunteers being involved from the beginning of the movement (Saunders, n.d.). There are a median of 167 volunteers in UK hospices, of whom an estimated 75% are women, and a median of 85 volunteers have direct patient or family contact (Burbeck, Low, et al., 2014).

It is estimated that volunteers reduce hospice costs by around 23% (Help the Hospices, 2006). There are approximately 160,000 volunteers, donating 23 million hours with an estimated economic value of £150 million (Scott, Jindal-Snape, & Manwaring, 2018). Volunteers are therefore essential to the sustainability of hospices (Scott et al., 2018).

In the UK volunteers are involved in all areas of hospices – including trustees – but the largest proportion (21%) are involved in fund-raising in the retail sector (Help the Hospices, 2003). Of those with patient and family contact, who are the focus of this thesis, the most recent survey reported that the majority are involved in day care and a minority in home care services (Burbeck, Low, et al., 2014). The survey also found that, across these services, volunteers are most likely to be engaged in greeting patients and visitors, serving meals and drinks, giving emotional care to patients and their families, and sharing a hobby. In around half of organisations where volunteers were involved with inpatient care they sat with patients in the final hours of life. Giving physical care to patients was the least common activity involving volunteers in both inpatient and home care settings. The survey also found that some volunteers offered their professional skills, that is skills requiring a professional qualification, typically beauty therapists and hairdressers, complementary therapists and spiritual care workers.

As I show in Chapter 2 it can be argued that the involvement of volunteers in hospices was largely pragmatic, helping the nascent movement to become established outside of statutory services and, therefore, statutory control. They helped to produce the 'alternative' feel of the movement and were eulogised as providing a different kind of care (Guirguis-Younger et al., 2005). However, volunteering is also recognised as essential to the economic viability of hospices (Scott et al., 2018). All this generates a contradiction between whether volunteers are 'complementary' or 'substitutive' (Sevigny, Dumont, Cohen, & Frappier, 2010, p. 743). With the increasing bureaucratisation and professionalisation of hospice care, and resulting professionalising forces in volunteering, this has created tensions.

1.7 The aims of the thesis

This thesis aims to explore how these tensions produce the role of the volunteer in patient- and family-facing roles based on participant observation, 'extended conversations' with senior staff and an analysis of hospice documents.

1.8 Outline of the thesis

In this chapter I have:

- outlined the development of my interest in volunteers in hospices;
- introduced the theoretical framework on which the study is based;
- provided background information about palliative care in the UK setting;
- indicated what I set out to achieve in this study, and how.

In the next chapter I contextualise the volunteer role further by examining the changing nature of death and dying in Western societies, the origins of the hospice movement, its ideology and maturing of the contemporary movement. I also explore the broader picture of volunteering in the UK before discussing how the hospice volunteer role is understood in the contemporary movement. Lastly, I introduce the main theoretical ideas I use to interpret my data. I also present Hockey's (1990) model of the patient's 'journey' through care which I use later as a structural device to order Chapters 5 to 8.

Chapter 3 provides an account of my methodological approach and describes the methods I used. It introduces the fieldwork sites and the volunteers and staff in each.

In Chapter 4 I examine the spaces and materiality of the fieldwork sites, and their role in 'defending' the life-death boundary and sequestering death drawing on Lefebvre's (1974/1991) theory of social space and Goffman's (1959/1990) theory of regions. I show how the volunteer role was constructed in relation to the life-death boundary through the imposition of spatial boundaries which excluded volunteers from some spaces used by staff.

In Chapter 5 I explore the volunteer role in the day hospice. I employ Goffman's (1959/1990) theory of dramaturgy to show how the hospice 'performed' 'living', shaping the volunteer role which was largely concerned with hospitality. Death, although not literally present in the sessions, intruded from time to time. Volunteers worked with staff to patrol the life-death boundary to minimise this encroachment but were kept outside clinical and professional boundaries.

Inpatient unit volunteers (Chapter 6) also helped to produce 'living' through hospitality, focused mainly on food practices. Unlike in the day hospice, death was present in this setting. I show how temporal, spatial, organisational and clinical boundaries kept volunteers away from the life-death boundary which was approached only by 'trained' staff. I suggest that since volunteers were not part of the medical model of care, they were marginalised at the bottom of the social hierarchy. This highlights difficulties in involving volunteers alongside paid staff and I suggest that volunteering may be incommensurable with the medical model.

In Chapter 7 I step away from the patient's journey through care to focus on volunteers who offered their professional skills. This group of volunteers undertook 'bodywork' on dying patients crossing the boundary into the territory of paid staff. Drawing again on Douglas (1966/2002), I suggest that these volunteers were 'matter out of place' with those in the day hospice, mostly complementary therapists, treated as ambiguities and those in the inpatient unit, care assistants, as anomalies. I argue that this demonstrates most clearly how death was for 'professionals' and that this was defined, not by the skills a person possessed, but by their employment status.

In Chapter 8 I again show how death was for 'experts' by returning to the hospice 'journey'. Here I show the volunteer role in producing 'living' by helping bereaved relatives move from death back to life. Unlike other volunteers, those in the bereavement team had no contact with patients and, therefore, no direct contact with death and dying. However, by contrast with other volunteers, they received a great deal of training and supervision but also enjoyed the most autonomy compared with other groups.

In the final chapter I draw my findings together and consider possible explanations using the theoretical lens of liminality, a review of the discursive practices which position volunteers as *un*-professional, and a consideration of the extent to which volunteering can be seen as a kind of 'work'. I highlight the unique contributions the thesis makes to the literature, provide some methodological reflections and consider the strengths and weakness of the research, together with suggestions for further research. Finally, I consider the implications of the findings for practice.

Chapter 2. The hospice movement and volunteers: origins and development

In this chapter I contextualise the role of volunteers in hospices and introduce the main bodies of literature and theoretical approaches I have used to explain and interpret my data. The chapter covers three areas: the origins and development of the modern hospice movement (parts one to three); volunteering in the UK and the volunteer role in hospices (parts four to six); and theoretical approaches to boundaries and performance (parts seven and eight).

To explain the origins and development of the modern hospice movement, I briefly examine the changing context of death and dying in the twentieth century and the growth of modern medicine. I explore the early development of the movement itself and its ideology and philosophy of care, before discussing how the contemporary hospice movement responded to the challenges of marketised healthcare. I then examine how this maturing of the hospice movement may have affected the volunteer role, focusing on tensions between volunteers and paid staff, and theoretical approaches to these. Since the key to my thesis was understanding how the life-death boundary was managed by hospices and therefore how this informed the construction of the volunteer role, I examine the work of Mary Douglas, whose ideas helped me to understand this and other boundaries. In the final part, I introduce the ideas of Erving Goffman regarding 'performance' which were helpful in exploring the gap between ideology and practice.

The focus throughout is on the UK setting.

2.1 The changing context of death and dying

The modern hospice movement can be seen as the product of, not only opportunities created by the reorganisation of UK healthcare in the period after the Second World War (Clark, 1999a), but also of a 'radical critique' of what became a medicalised approach to death and dying (James, 1994, p. 103). In this section, I discuss the origins of this critique.

Death and dying in the twentieth century have been characterised as becoming 'hidden' and 'taboo' compared with earlier times (Ariès, 1981). Taking an historical perspective, Ariès argues

that in previous eras (covering the fifth to the nineteenth centuries), death was much more part of everyday life because people encountered it more frequently, and because death was more likely to take place where people were living. Three reasons explain the transformation in the place and management of death and dying in Western societies during the twentieth century.

First, improvements in public health during the early years of the twentieth century led to an increase in average life expectancy. In 2000 approximately 80% of deaths were of people over 65 years of age whereas in 1901 only 20% of deaths were in this age group (Griffiths & Brock, 2003). Therefore, death not only became a less common event, but also less ‘disruptive’ since fewer people died at an age when they were most likely to be raising families and being economically active (Blauner, 1966). Second, in the UK, since the inception of the NHS in 1948, healthcare became available to more people. Advances in medicine increased the range of treatable conditions and technological improvements meant that care was centralised in hospitals (Field & James, 1993). Third, changing societal and demographic factors, such as the increased presence of, and change in attitudes to, women in the workplace, meant that sick or dying people were more likely to be cared for in an institution than in the home (Field & James, 1993).

The outcome of these changes was that, as the twentieth century progressed, the ‘care’ of dying people was increasingly taken out of the home into institutions. In 2017 around a quarter of deaths occurred in the home, with nearly twice as many taking place in hospital, and the remainder in other institutions (see Table 1).

Place of Death	Number of deaths	% of Total Deaths
Hospital	228,487	46
Home	117,522	24
Care home	111,230	22
Hospice	28,965	6
Other	10,822	2
TOTAL	497,026	

Table 1 Percentage of deaths in England in 2017 by place of death ³

³ Calculated from Office for National Statistics’ figures (ONS, 2018).

2.1.1 Medical model and professionalisation of the workforce

Modern medicine presented itself as the product of scientific, rational enquiry (Hockey, 1990), which could 'cure all evils' (James & Field, 1992, p. 1364) and, in the UK, focused on the 'modernising ethic' of the new NHS (Clark, 1999a, p. 226-227). The Cartesian separation of mind and body characteristic of 'scientific' enquiry helped to medicalise illness, with the body becoming a site for the 'invasion' of disease while the 'self' looked passively on (Walter, 1994). This is exemplified by the ubiquitousness of 'battle' metaphors in cancer treatment (Sontag, 1978/1979). Within this paradigm, death was deemed a medical failure (Clark, 1999a).

A consequence of this medicalisation of illness was the adoption of the medical model of care. It is hard to find a precise definition (Fawcett, 2017) but the term was originally coined by Laing (1971) to refer to the structured approach to treating a patient's illness in which doctors were being trained (complaint, history, examination, diagnosis, treatment (p. 41)). The model has come to be associated with hierarchy with doctors at the head (Fox, 1992) and the patient taking a largely passive role (Fawcett, 2017). The model also incorporates professionalisation processes through which an occupational group (such as nurses or psychiatrists) defines and protects itself (described in section 2.3.2). In Chapters 6 and 7 I consider whether the adoption of this model in hospice care may be incommensurable with volunteering. The medical model, with its focus on treatment and cure, thus separated life from death. The removal of death from domestic settings to institutions literally and symbolically separated life and death (Hockey, 1990). It is this separation which the nascent hospice movement deliberately sought to reintegrate (Hockey, 1990).

2.2 The modern hospice movement: a new approach

Although medical advances extended the period of 'dying' (Lawton, 2000) so that 'quick dying' of the pre-modern era was now replaced by 'slow dying' (Scambler 1991, p. 94), the needs of dying people were not a specific focus of the new NHS (Hockey, 1990, p. 63). Some provision had been initiated outside of statutory services. These included the Marie Curie Memorial homes for terminally ill people with cancer, but the care provided was relatively basic since these homes were run largely by untrained staff, with limited medical involvement (Clark, 1999a). In addition, an interest in improving care in the nineteenth century both in Europe and in America, had previously led to homes for dying people being established. In London and Dublin, five were founded between 1879 and 1905, two of which adopted the name 'hospice': St. Joseph's Hospice

in Hackney, London, and Our Lady's Hospice for the Dying in Dublin. The others (all in London) were the Hostel of God, St Luke's House, the Friedenheim and the Home of the Compassion of Jesus.

However, in the two decades after the start of the NHS, concerns started to be raised about the state of care for dying people (Clark 2007; 1999a) with autobiographical and fictional accounts bringing the matter to the attention of the wider public (James, 1994). Academic studies reported similar findings (for example, Glaser and Strauss, 1965; Sudnow, 1967), although were criticised for nostalgically romanticising a pre-modern era when death was somehow 'better' (Lawton, 2000). However, their overall conclusions were supported by two large-scale reports in the UK highlighting the problems caused by lack of care for dying people: the joint Marie Curie Memorial and Queen's Institute of District Nursing (J.N.C.S.C., 1952), and Glyn Hughes' report for the Calouste Gulbenkian Foundation (Glyn Hughes, 1960) (Hinton, 1972; Clark, 1998). Thus, the impetus was provided for the founding of the modern hospice movement which is generally considered to have begun with the opening in 1967 of St Christopher's in south London, UK, by Dame Cicely Saunders (James & Field, 1992).

Dame Cicely promoted a new approach to caring for dying people which emphasised the 'quality' of the dying process focusing on 'living' rather than on dying, or as Dame Cicely put it 'live until you die' (Twycross, 1990, p. x).

2.2.1 'Total pain'

Key to the new approach was the alleviation of 'total pain', that is, physical, social, emotional and spiritual pain, although the control of physical pain was central to this endeavour (Clark, 1999b). Previously, pain medication, notably opiates, was used only when the patient was already in pain largely because of a fear among healthcare professionals that 'overuse' could cause addiction or unwanted elation (Lewis, 2007; Saunders & Clark, 2002). Staff at St Luke's House had begun to develop ideas around giving analgesia more frequently, and Dame Cicely developed this while she was working at St Joseph's Hospice, resulting in an approach based on anticipating pain and giving medication regularly (du Boulay and Rankin, 2007; Lewis, 2007).

Also fundamental to the concept of 'total pain' was the link between physical and mental suffering (Clark, 1999b), in particular, reducing *fear* of pain (Leming, 2003). Dame Cicely was influenced in this by other clinicians working in the field, including John Bonica in the US (Lewis, 2007) with whom Dame Cicely corresponded, for example, about psychiatric techniques in

respect of pain relief (Saunders & Clark, 2002: letter to Professor J.J. Bonica, 1966). In addition, Dame Cicely believed that it was important for patients to know their prognosis, which up until this time had commonly not been disclosed. She reasoned that patients were happier if they were able to come to terms with their condition so that, for example, they had time to put their affairs in order (du Boulay & Rankin, 2007).

At the core of the hospice movement's mission, therefore, was the concept of producing a 'good death' that is, reclaiming 'natural death' from 'modern' medicalised and technologised death (Hart, Sainsbury, & Short, 1998; Palgi & Abramovitch, 1984). A good death is frequently articulated as 'death with dignity' or 'peaceful death' (James & Field, 1992, p. 1367). It is death free from chaos, for example, that caused by pain. Central to producing a 'good death', therefore, was Dame Cicely's approach to pain relief, essentially a medical procedure. Thus, as Seymour (1999) points out, achieving a 'good death' requires considerable medical support despite the contradiction this produces with the movement's anti-medicalisation stance. However, ideologies are not necessarily internally consistent and may produce contradictions (Donald & Hall, 1986). Although ideology is a highly contested term, in essence, it is an organising set of principles which help to articulate goals, provide motivation, and influence behaviour (Field & Johnson, 1993).

2.2.2 Hospice ideology

The hospice movement's ideology focuses on three ideas: holistic care, non-hierarchical multi-disciplinary teams, and the family as the unit of care (Field & Johnson, 1993).

Holistic or 'total' care prioritises personal choice and control (Seymour, 1999), and resonated with the development of person-centred medicine in other healthcare settings at that time, for example, childbirth (Seale, 1998a). This constructed the patient and carer as members of a healthcare *team*, in theory suppressing a healthcare hierarchy (Seale, 1998a). Hospice 'total care' also involved a range of professionals, including occupational therapists and chaplains (Abel, 1986). Important in the hospice ideal, therefore, was the redefinition of professional relationships, in theory, including volunteers.

The focus on the family as the unit of care reflected the growing movement in healthcare towards patient-centred care (Seale, 1998a). In a letter to Colin Murray Parkes, a psychiatrist with a special interest in bereavement, Dame Cicely referred to 'the work of families both while the patient is ill and afterwards' (Saunders & Clark, 2002, letter dated 14 June 1966, p. 103). Dame Cicely asked

Murray Parkes to work with her at St Christopher's where he recruited volunteers as bereavement counsellors⁴ as part of a family service (du Boulay & Rankin, 2007). Bereavement support (including pre-bereavement care) has therefore been part of hospice services from the beginning, with activities including social events, support groups, befriending and one-to-one support (Payne, 2002). I discuss volunteers involved in bereavement care in Chapter 8.

Providing services for bereaved relatives shows how hospice ideology expressed the dying process as a 'journey' with the patients' relatives passing through a temporary state of bereavement to return to living (Froggatt, 1997). Indeed, the origins of 'hospice' invokes notions of journeying (Stoddard, 1992). In pre-industrial societies providing for travellers' needs while ensuring their safety was a moral imperative (Lashley, 2000). Hospices were places where pilgrims could rest or be cared for if they were sick or dying (Stoddard, 1992). Since the term derives from the Latin *hospes* meaning both host and guest it also embeds the notion of hospitality into hospice ideology, as I discuss in Chapter 5 with regard to the role of the volunteers in the day hospice.

Hockey (1990) proposes that, the hospice movement, by focusing on the relationship between life and death as a *process*, constructs living and dying as a 'biological continuum' (p. 155). While the patient is supposedly 'living until they die', following the patient's death, those who are bereaved are brought 'back to life'. The continuum is illustrated in Appendix A and I use it as a structural device to sequence Chapters 5 to 8 in order to illustrate the differences between volunteer roles in each setting and so develop my thesis.

Dame Cicely deliberately focused on hospice as *home* (du Boulay & Rankin, 2007) and this is still important for the modern movement, not only for the 'material ideology' (Miller, 1984, p. 37), which I describe in Chapter 4, but also other practices such as those concerned with food, which I discuss below and in Chapters 5 and 6. 'Normalising' death by invoking home to make it feel less frightening is also an important part of the hospice project (Worpole, 2010). As I observed, the role of host is central to that of volunteers (Help the Hospices, 2012, p. 8), and I explore this in Chapters 5 and 6.

⁴ It was not unusual to involve volunteers in this role since the bereavement counselling service, Cruse, had done so since it began in 1959.

A Christian ethos was also very important in the establishment of the modern hospice movement (Hockey, 1990), and central to Dame Cicely's personal motivation. However, she struggled with the extent to which the 'home' (i.e., what became St Christopher's) should have a religious basis (du Boulay and Rankin, 2007). A Christian influence can still be seen in the many contemporary hospices named after Christian saints (Hockey, 1990).

Dame Cicely was aware of the importance of establishing her first home for dying people outside of mainstream healthcare in order to retain flexibility and to introduce new ideas. In her 'Scheme' for what became St Christopher's Hospice, she stated: *'The Hospice or Home is not to be part of the National Health Service. We want to be independent, because we need freedom of thought and action'*, (Saunders, n.d.⁵, p. 7). In challenging the medicalisation of death and dying the new movement established itself as a *counter* movement, reflecting the *zeitgeist* of the 1960s which saw such movements developing in other arenas in industrialised western societies, including in mental health, the free school movement, free co-operatives and the rise of communes (Abel, 1986). These were characterised by 'a nostalgia for simple, old fashioned ways, dissatisfaction with bureaucratic and authoritarian institutions, faith in the power of nature, a determination to avoid domination by experts, and a desire to improve the quality of personal relationships' (Abel, 1986, p. 71).

As this section has shown, all are identifiable in the ideology of the hospice movement. A further aspect in accomplishing Dame Cicely's vision and establishing the hospice movement as a counter movement, was the adoption of voluntarism. This involved volunteers not only in raising the funds to build St Christopher's in the first place, but also in the hospice itself helping to promote the 'alternative' feel of the early movement.

2.2.3 Volunteer involvement

From the outset Dame Cicely employed a paid member of staff, Sheila Hanna, as Volunteer Services Organiser. Hanna described how it was planned to involve volunteers 'from the local community and from the families and friends of the patients, including most probably those that

⁵ Although the *Scheme* itself is not dated, Dame Cicely sent a copy to Brigadier Glyn Hughes in a letter dated July 1959 asking for his opinion (Saunders and Clark, 2002, p. 15).

had been bereaved' and 'the use of volunteers in this field was nebulous and I felt myself groping very much in the dark' (Hanna, 1975, p. 1).

As St Christopher's developed, more volunteers were involved, 'between 120 and 130' by 1975 when the hospice had 18 elderly residents ⁶, 54 patients, an outpatient clinic, a play school for children of staff, a research department, general administrative offices, study centre and family aftercare service, all of which involved volunteers, as well as in the main kitchen, the stores, reception and visitors tea bar, Red Cross trolley shop and library service, and a rota of volunteer car drivers to call on (Hanna, 1975).

The volunteers quickly became indispensable. In a letter to Sue Ryder in 1969, Dame Cicely wrote:

We are very impressed by what they contribute ... [but there] must be someone to organise them (Saunders & Clark, 2002, p. 137).

And in 1971 she wrote to 'Mrs Y Dale', who was setting up a new hospice:

'You will get staffing problems.... and once you ... have a proper supply of volunteers you will be alright [sic]' (Saunders & Clark, 2002, p. 142).

Volunteers reflected 'special' types of more egalitarian relationships than had previously been the case between 'patient' and 'professional' caregivers (Froggatt, 1997). However, the extent to which a genuinely non-hierarchical care team was established is unclear. The following excerpt from St Christopher's Hospice annual report for 1972-3, demonstrates an intention to give an appearance of a flattened hierarchy, but one which does not include volunteers:

Another change has symbolised our efforts to become more truly a family. Nurses of all grades have always worn blue uniforms, although there has been some difference in style. Students wear the same, although they do not wear caps. Our domestics and orderlies have now joined them in the same colour, which blends so well with the volunteers' pink. (St Christopher's Hospice, 1973, p6).

⁶ St Christopher's originally included a home for older adults.

Thus, the difference between volunteers and paid staff was *visually* apparent, and it appears that Dame Cicely saw volunteers as a separate resource from staff. Recalling the early days of St Christopher's Dame Cicely describes how Lilian Pipkin, 'a model manager of volunteers as well as staff' (Saunders, 2002, p.vii) who Dame Cicely had come across when she herself volunteered at St Joseph's 'came to share some of her wisdom with the staff as it built up its own nursing and volunteer team' (Saunders, 2002, p.vii).

Therefore, volunteers were not only involved in the hospice movement from the beginning, but were both distinct from staff and important in resource terms. However, in hospice movement ideology, volunteers became eulogised as providing a unique kind of care (for example, Guirguis-Younger et al., 2005). As I argue in this thesis, there is tension between ideology and reality. I examine literature on volunteers in the contemporary hospice movement in section 2.5.

In this section I have discussed how the hospice movement began as a counter movement critiquing the *status quo* with regard to the care of dying people. It changed care through very real improvements in how medication was used to control pain, and attempted to confront death and dying rather than to hide it. However, it legitimised itself partly through a 'harking back' to 'tradition' (Lawton, 2000, p. 11) establishing itself as a counter movement, evoking the cause of 'naturalness', privileging the individual in controlling their care, and placing voluntarism central to the original ethos. It emphasised the 'family' as the unit of care, and introduced the concept of holistic care, embodied by the multi-disciplinary team. The ideology was inspired by the concept of the good death conceptualised as a mythical less-developed 'traditional' or 'natural' death based on a critique of the increased medicalisation and technologizing of death and dying and a reaction to it. There is some irony in the way that the hospice movement was similar to the healthcare system the NHS had replaced, not only in the original plan to fund it by local subscription, but also in the involvement of local doctors, and in its religious and philanthropic associations (Clark, 1999a).

Dame Cicely established St Christopher's not only to provide a new way of caring for dying people based on the principle of 'total pain', but also to provide education for healthcare professionals and to undertake research. The combination of these three factors marked the opening of St Christopher's as the beginning of the 'modern hospice movement' (James & Field, 1992). Other

hospices quickly became established both in the UK and around the world, and by 1976, a hospice *movement* could be said to have developed (James & Field, 1992). ‘Hospice’ thus became both a philosophy of care and a physical place (Corr, 2007). Dame Cicely’s approach also provided the framework of what became the medical speciality of palliative medicine.

In the next section I examine tensions that have arisen as the hospice movement has matured, which bring particular issues for volunteers.

2.3 The contemporary hospice ‘movement’: bureaucratisation and professionalisation

As the hospice movement matured, it faced challenges both from within and from outside. These included pressures caused by the day-to-day running of hospices (James & Field, 1992), and by the establishment and maintenance of a relationship with mainstream healthcare (Abel, 1986). These challenges made it difficult to maintain the original ideological vision, such as the non-hierarchical approach (James, 1994), which I argue in this thesis affected the way the volunteer role is constructed.

2.3.1 Relationship with statutory services

Although being clear that St Christopher’s should be established independently of the NHS, Dame Cicely understood that a relationship with statutory services would be needed. For example, she envisaged that some patients would be referred from, and be paid for by, the ‘Regional Board’ (i.e., local statutory services) based on the model operating at St Joseph’s where ‘the Board have control of admissions’ (Saunders, n.d., p. x). She also suggested that the location for the new ‘home’ should be South East London in order to be near St Thomas’s Hospital ‘which we hope will be interested in it’ (Saunders, n.d., p. 9). In fact, within three years of the opening of St Christopher’s, the NHS was contributing a substantial proportion of the funding for its inpatient service, and entirely funding its outpatient and home services (Saunders & Clark, 2002). Widespread public support helped the movement to grow quickly resulting in a substantial increase in the number of hospices (Lawton, 2000; James, 1994). However, hospices were expensive to run even with the involvement of volunteers (James, 1994). Running costs tended to exceed the money that could be raised and, by the 1980s, most hospices were partially funded by the NHS (Lawton, 2000). One consequence of this was the development of hospice units within the NHS and, since the 1990s, palliative care services, as they came to be known, were increasingly included in the NHS’s organisational framework (Lawton, 2000). Therefore, far from

24

being an independent movement able to innovate without the structure of mainstream services, it became increasingly bureaucratised and institutionalised (James & Field, 1992).

However, the process was two-way, with the movement also becoming involved in policy making (James & Field, 1992). One of the original aims of the movement was to see its innovative ideas about the care of dying people incorporated into mainstream care, and therefore to 'plan for our own obsolescence' (Wilkes, 1981, p. 186). Although many innovations from the hospice movement's approach to care have been incorporated into the mainstream (Saunders, 1998), the contemporary movement now sees itself dovetailing with the NHS and other care providers (for example, Help the Hospices, 2013). In reality, hospices compete with other providers for contracts to run local services (Help the Hospices, 2013), and consequently must meet similar standards of care (Care Quality Commission, www.cqc.org.uk). This may have led to a focus on cost-effectiveness at the expense of maintaining the hospice ethos of care (Lawton, 2000). In section 2.5 I argue that this creates a tension in the involvement of volunteers.

2.3.2 Professionalisation

With increased bureaucratisation and institutionalisation come professionalisation (James & Field, 1992; Paradis & Cummings, 1986). This can be seen as 'a strategy of occupational control which controls the relationships between experts, patrons and clients' (Bond, 1992, p. 17, drawing on Turner, 1987). Common practices include refining and guarding the knowledge base, setting criteria for membership of the group (for example, gaining entry by formal examinations), and demarcating practice (Davies, 2001). The process of professionalisation of healthcare workers could be said to have begun with the establishment of doctors as 'professionals' marked by the institution of the General Medical Council in 1858 (Blane, 1991). Continued professionalisation has spread to other roles, such as nurses, for which a degree-level qualification is now required (<https://www.nmc.org.uk/education/becoming-a-nurse-midwife-nursing-associate/>). However, as discussed above, part of the ethos of the hospice movement involved an egalitarian approach to care embodied in the multi-disciplinary team (including volunteers), in effect, an anti-professionalisation standpoint.

To survive, the hospice movement needed to be accepted by the medical establishment (Clark, 1998) which meant that its novel approach to the care of dying people had to be seen as medically effective (Seale, 1998a). The new movement also required staff (Clark, 1998). Initially, there was no specific professional status or career structure for healthcare professionals caring

for dying people (terminal care as it was known) as in other areas of medicine making it unattractive as a career move (Small, 2000). Eventually the Association for Palliative Medicine was established in 1985, followed by the recognition of palliative medicine as a medical speciality by the Royal College of Physicians in 1987 (Hillier, 1988; Overly & Tansey, 2013). This effectively marked the *re*-professionalisation of the care of dying people (James & Field, 1992; James, 1984). Help the Hospices,⁷ a national umbrella organisation set up to support hospices, recommended that all patient care should be supervised by a doctor (James & Field, 1992). Previously some hospices had introduced nurse-led care, blurring the traditional nurse-doctor hierarchies characteristic of the NHS. Volunteers do not have a professional organisation outside the hospice and, as I show in Chapter 6, find themselves at the bottom of the new hierarchy.

2.3.3 Medicalisation

James (1994) noted that the increased professionalisation in the hospice workforce, and the recruitment of staff from the NHS, meant that the emphasis of care would likely tend towards the physical element of 'total care', since this is the focus of the biomedical system in which staff are trained. In her study of the personhood of hospice patients, Lawton (2000) argues that the increasing deterioration of the body during the dying process made it difficult for the hospice to enact 'total care' in practice. The overwhelming nature of some patients' physical needs meant that these took precedence over other aspects of care. In addition, she noted that the achievement of 'total care' could be undermined by economic considerations generating pressure to discharge a patient from hospice inpatient care (Lawton, 2000). Further, the requirement for patients to be classified as 'life-limited' (McDaid, 1995) before they can be referred to hospice services, involves medical professionals to make the appropriate 'diagnosis', effectively medicalising hospice care.

According to Hockey (1990), the adoption of the medical model in healthcare has resulted in the continued maintenance of a boundary between life and death within Western societies, manifesting itself in spatial, temporal, medical, social and linguistic boundaries. These boundaries can be seen in aspects of the contemporary hospice movement, despite its ideological aim to reintegrate life and death (Hockey, 1990). For example, spatial boundaries, which I explore with regard to the hospice in Chapter 4, are maintained by the sequestration of dying people in institutions, such as hospices, care homes and hospitals. Temporal boundaries are maintained by

⁷ Now Hospice UK

the discourse that death should be 'timely' otherwise it is not 'natural', such as death while family members from an earlier generation are still alive. Medical boundaries are maintained by a focus on the medical definition of death (Machado et al., 2007), rather than on its social meanings. Social boundaries are maintained by discourses surrounding bereavement and linguistic boundaries exist in the use of euphemisms for death, such as 'passed', being 'at peace' or 'at rest'. During the course of my fieldwork, I observed examples of most of these boundaries. As I will show in this thesis, it is the maintenance of the life-death boundary which constructs the volunteer role.

Before considering the existing literature on the volunteer role in the next section of this chapter, I introduce the idea of Foucault's (1984/1986) heterotopia which provides a theoretical lens through which to view the contemporary hospice movement. Heterotopia are ambiguous places defined in opposition to other places, and which represent an alternative social order (Street & Coleman, 2012).

2.3.4 Hospice as heterotopic

The characteristics of heterotopia - *other places* - derive from their function as places for those who are in crisis or whose behaviour 'deviates' from societal 'norms', that is, 'others', for example, prisons, psychiatric hospitals and retirement homes (Foucault, 1984/1986). Since death is deviant insofar as it is a medical failure (Hinton, 1972) and can also represent a crisis (Douglas, 1966/2002), hospices are heterotopic in that they sequester dying people from their communities. Foucault (1984/1986) suggests five other principles of heterotopia, which I argue can all be applied to the hospice movement:

First, the function of heterotopia can change over time. Foucault (1984/1986) cites the example of cemeteries, which at one time in Western societies, were placed centrally in communities, usually around a church reflecting the medieval belief in the literal resurrection of the body at the Day of Judgement (Revelation 20:11-15). However, with increased atheism and 'obsession with death as an 'illness'' (Foucault 1984/1986, p. 25), cemeteries were located on the outskirts of communities, changing their meaning but retaining their heterotopic quality. With regard to the hospice, as I described in Chapter 1, the original function of a 'hospice' was a place for travellers to rest.

Second, Foucault (1984/1986) describes that it is possible for several types of space to be juxtaposed within a heterotopia. In Chapter 4, I describe how the day hospice spaces – living space – existed alongside the dying spaces of the inpatient units.

Third, Foucault (1984/1986) links entry to heterotopia with a break with regular time. Again, he cites the example of the cemetery. A person who has died has moved from mortal time to immortal time. Entry to hospice care usually marks a shift in a patient's journey from treatment aimed at cure to symptom control and to 'dying'.

Fourth, heterotopia are isolated by a system of entry. In the case of the hospice, access for patients is through a 'diagnosis' of dying, as I point out above.

Last, heterotopia have a function in relation to all the *other* space, in particular, to be a 'perfect' version of the other space. Foucault (1984/1986) gives the example of colonial settlers who establish a perfected replica of the place or society they left behind. In the case of hospice, I would argue that its ambition to create the 'good death' which is otherwise unachievable in society fits this principle.

The notion of the hospice as heterotopic provides a theoretical lens through which to understand the contemporary hospice movement. It encapsulates the contradictions between the hospice movement's original mission to reintegrate life and death, and the continued maintenance of the life-death boundary by the medical model (Hockey, 1990). As I discussed above, from its origins as a counter movement the hospice movement has co-existed with mainstream healthcare producing pressures from increased bureaucratisation, the professionalisation of its workforce and the effective re-medicalisation of death and dying. Before considering how these pressures may have impacted on the volunteer role in hospices, I examine the wider topic of volunteering in the UK.

2.4 Volunteering in the UK

I begin this section by examining the broad landscape of 'formal' volunteering in the UK, that is 'unpaid help given as part of groups, clubs or organisations to benefit others or the environment' (Kitchen, Michaelson, Wood, & John, 2006, p. 6), into which category hospice volunteering falls. I continue by considering volunteering in health and care settings to examine a number of issues

which also apply to volunteering in hospices, thus setting the scene for the more detailed inspection of the literature on hospice volunteers which follows.

2.4.1 UK volunteering: how many, who, where and why?

The most recent Community Life Survey 2018/2019 showed that the number of people volunteering 'formally' at least once a month had fallen from 27% in 2013-2014 to 22% (Department for Digital, Culture, Media and Sport, 2018). The demographic profile of this group was approximately equally balanced between men and women but there were differences between age groups, with people aged 25-34 years the least likely to volunteer and those aged 65-74 years the likeliest to do so (15% versus 28%). The most recently available data for formal volunteering by ethnic grouping showed that 20% of people who identified as being from a black or minority ethnic group volunteered formally at least once a month compared with 28% of those who identified as white (Community life survey 2015/16 reported in Hornung, Egan, & Jochum, 2017). Although the data show that regular volunteering is not uncommon, the Community Life Survey 2018/2019 also reported that only 7% of respondents said they had volunteered consistently over their lifetime and 'always more heavily than lightly' (p. 16). This observation supports an earlier finding that there is a 'civic core' of volunteers who provide a disproportionate number of volunteer hours (9% of volunteers providing 51% of volunteer hours) (Mohan & Bulloch, 2012). The members of this group were most likely to be women, to have degree-level education, have a higher salary compared with other volunteers and to practise a religion. No information was provided about ethnicity.

Data from a UK-based survey of over 10,000 people showed significant differences in volunteering rates by sector. Of those who volunteered at least once during the previous year (termed 'recent' volunteers), 67% did so in a 'civil society' group or organisation (that is, the third or voluntary sector), 17% in a public sector organisation and 10% in a private sector organisation (McGarvey et al., 2019). Regarding the 'business' of the organisations to which people offered their time, those providing recreational or leisure activities were most commonly cited regardless of sector (20%), followed by local community or neighbourhood groups (20%), health, disability or social welfare organisations (18%), sport/exercise groups (15%), settings involving older people (14%), youth/children's activities outside of school (14%) and religious organisations (11%) (McGarvey et al., 2019). The most common activity undertaken by recent volunteers involved organising and running an event, with 39% of respondents reporting this, while 28% said they helped with secretarial, administrative or clerical work and 27% raised money or took part in sponsored

events. Less commonly cited tasks included providing transport/driving (15%), handling money (14%) and visiting people (10%) (McGarvey et al., 2019).

Volunteer motivation is of central importance in the recruitment and retention of volunteers (Saxton et al., 2015). Krutkoski's (2014) typology divides volunteer motivation into three overarching categories: altruistic motivations (such as 'giving something back'), obligatory motives (moral or religious duty) and instrumental motivations (such as developing new skills). This grouping was reflected in the findings of the Community Life Survey 2018/2019 (Department for Digital, Culture, Media and Sport, 2018) where the most common motivation cited by respondents was to 'improve things/help people' reported by 45% of volunteers in formal organisations. The next commonest motivation, given by 31% of respondents, was that the cause for which they volunteered was important to them. Meanwhile, 14% said they volunteered because helping people was part of their religious belief or philosophy of life, 16% indicated that they wanted to learn new skills and 8% that they volunteered to improve career opportunities. However, these data were from volunteers across a wide range of organisations and the relative importance of particular motivations is likely to vary between sector, organisation and individual volunteer (Saxton et al., 2015).

Another issue in retaining volunteers is the extent to which they are satisfied with their experience. In McGarvey et al.'s (2019) survey (see above), a high proportion (93%) of volunteers said they were at least 'fairly satisfied' with their involvement. The survey found that satisfaction was strongly associated with aspects of organisational culture, specifically that volunteers were respected and trusted by others in the organisation and that they felt well supported, had sufficient recognition for their contribution and considered that they 'belonged'. On the other hand, volunteers were less likely to be satisfied if they considered that an organisation could be better organised with regard to volunteers or, more broadly, that an organisation 'wasn't going anywhere' (McGarvey et al., 2019, p. 40). Of relevance to hospice volunteering (see section 2.5.4), one source of dissatisfaction concerned volunteer roles being too structured or formalised with twice as many recent volunteers in public sector organisations citing this issue compared with those in civil society organisations (20% versus 10%).

An understanding of what prevents people from offering their time is also important. The Community Life Survey 2018/2019 (Department for Digital, Culture, Media and Sport, 2018) found that barriers to volunteering included work commitments (49% of those who did not volunteer at least once a month) and childcare responsibilities (23%). Indeed, factors such as an aging

population, rising retirement age, an increase in the numbers of people caring for their grandchildren and an expanding range of leisure opportunities have all been identified as negatively affecting the availability of potential volunteers (Rochester, 2006). The last issue was also highlighted to me by the Volunteer Manager at one of my study settings who told me that, compared with when she was first in post about ten years previously, fewer potential volunteers now offered their time to the hospice. In her view this was because there was now a wider choice of organisations in the local area offering volunteer roles, although the issues listed above are also likely to be relevant. In addition, according to Howlett (2009) volunteers have high expectations and many want a more 'personalised' experience deploying skills they already have rather than being 'forced into a mould' (Saxton et al., 2015, p. 48). As one interviewee in Saxton et al.'s (2015) research put it, '(...) we're quite good at involving high numbers of people in relatively low skilled roles, what we want to get better at is also involving small numbers of people in higher skilled roles' (p. 48). All these factors present both challenges and opportunities regarding volunteer involvement and emphasise the importance of effective volunteer management at all stages of the volunteer 'career' (Rochester, 2006).

This section has provided an overview of the wider picture of volunteering in the UK, showing that formal regular volunteering is not an uncommon activity, particularly in voluntary or third sector organisations and in organisations providing recreational or leisure activities. However, a 'civic core' of volunteers is likely to account for most volunteering hours overall (Mohan & Bulloch, 2012). Unsurprisingly, the most common motivation for volunteering is to help other people. However, social and demographic changes present challenges in recruiting and retaining volunteers. Volunteers need to feel valued and to find satisfaction in their roles. This points to the importance of organisational culture in successful volunteer involvement which I discuss below in relation to volunteering in health and care settings (section 2.4.5). Before doing so I provide an overview of volunteering in these areas which include both statutory (mainly the NHS) and voluntary sectors (such as hospices).

2.4.2 Volunteering in health and care settings

Assessing the numbers of volunteers involved in health and care settings is difficult since surveys have different foci and methodologies. For example, from data in McGarvey et al.'s (2019) survey

(see above), which is the most recently available, I calculate that 18%⁸ of people who indicated that they had volunteered at least once in the previous year were involved in health, disability and social care organisations across all sectors. This contrasts with the previously available estimate which was based on data for England from the National Citizenship Survey (Department for Communities and Local Government, 2011) and showed that 27% of 'regular' formal volunteers were involved in health, disability and social welfare organisations, equating to around three million people (Naylor et al., 2013). Although the discrepancy may partly be accounted for by the fall in overall volunteering rates (see above), it may also be due to how volunteering in health and care was defined by researchers. Using a narrower definition (although it is unclear what this was) Buck (2016) calculated that around 1.7 million people volunteered in health and care services across the UK. The data in specific settings are also unclear. Galea, Naylor, Buck, and Weaks (2013) estimated that 78,000 people volunteered in acute hospitals in England, but Ross, Fenney, Ward, and Buck (2018) consider this figure to be an underestimate since they believe it did not include volunteers supported by non-NHS organisations such as the Royal Voluntary Service. There are also problems with arriving at accurate figures in social care settings. Data collected in 2018 combined volunteer numbers with those for bank and pool workers, agency staff and students (Fenton, Polzin, Arkesden, & McCaffrey, 2019). These data would be helpful in the present discussion if they could be disaggregated.

Despite problems with assessing the numbers of volunteers, it is clear that they are involved in a wide range of health and social care settings including hospices, community settings, hospitals, kindergartens/primary schools, home care, older people centres, mental health trusts, primary care and online volunteering (Naylor et al., 2013, based on Volunteering England, 2012). In community settings volunteers provide social support, advocacy and coaching for patients undergoing lifestyle changes, while in care homes roles include supporting people to eat properly and providing activities to improve wellbeing (Naylor et al., 2013). Roles in the NHS include ambulance 'first responders', social events organisers, interpreters, wheelchair pushers and flower arrangers (Boyle, Crilly, & Malby, 2017).

⁸ McGarvey et al. (2019) give percentage of volunteers in health, disability and social care (HDSC) by sector as follows: 67% in civil society organisations of which 20% are in HDSC; 17% public sector organisations with 16% in HDSC; and private sector 10% with 15% in HDSC. Therefore, 20% of 67% = 13.4%; 16% of 17% = 2.72%; 15% of 10% = 1.5%, so 17.62% overall.

However, involving volunteers alongside paid staff is not necessarily straightforward. For example, paid staff can feel threatened by volunteers in terms of job security, particularly if volunteers possess specialist knowledge (Netting, 2004). At the root of problems in integrating volunteer roles with those of paid staff is the relative status of volunteer and staff roles and how this is established (Naylor et al., 2013). While volunteer roles can augment those of paid staff (Hussein, 2011) adding capacity by undertaking tasks which would not otherwise be done (Boyle et al., 2017), doing so raises the question of whether volunteers are substitutive or complementary. Since this issue is of relevance to this thesis, I now consider some evidence in wider health care settings.

2.4.3 Volunteers: substitutive or complementary?

Some studies emphasise the volunteer role as supporting staff rather than being a distinctly separate role. I argue that how this support is seen (that is, as 'complementary' or 'substitutive') depends on how study respondents frame volunteer involvement. For example, a survey of 296 healthcare staff who interacted with volunteers in 34 NHS trusts across England described this involvement as providing practical support when staff were busy (Ross et al., 2018). (Twenty respondents also provided semi-structured telephone interviews.) Volunteer tasks cited in the study included collecting or delivering items, giving patients food, alerting staff to patient concerns, tidying up, serving tea and chatting to patients, mostly indicating a substitutive role. By contrast volunteers in a study undertaken in a range of UK statutory and voluntary settings (Naylor et al., 2013) considered that their role was not substitutive but was aimed at providing something extra to that of paid staff focused on 'enabling staff to get on with their jobs' (p. 15). Naylor et al. (2013) point out that volunteers were aware of staff concerns about substitution and had indicated that they would stop volunteering if this was the case. However, it could be argued that 'enabling staff to get on with their jobs' suggests that without volunteer support, staff would be overstretched. Other studies support this argument by showing that volunteer involvement allows staff time to do 'specialist' tasks, for example, administering medication (see McDonnell, McKeown, Keen, Palfreyman, & Bennett, 2014). Therefore, whether volunteers are 'substitutive' or 'complementary' may depend on how their role is perceived in individual organisations rather than by what tasks they undertake. It is also likely to be determined by organisational culture (discussed in section 2.4.5 below). How volunteers are seen is important since the perception that they are substitutive can raise a barrier to their involvement (Boyle et al., 2017).

Other study findings more clearly emphasise the distinctness – and therefore the complementary nature – of the volunteer role. Such studies commonly cite the fact that volunteers had time to interact with patients in a more social and relaxed way compared with staff whose conversations tended to focus on assessing needs (for example, McDonnell et al., 2014; also some respondents in Ross et al., 2018). One example highlighted how, in a study of breastfeeding peer support volunteers in a UK maternity ward, staff considered that volunteers provided a service which was ‘unique and distinct from professional support’ (Hopper & Skirton, 2016, p. 62). The findings highlighted that effective communication between volunteers and staff and the fact that both groups understood the boundaries of their respective roles were key to the success of the volunteer role. This latter factor was also identified by Gillard, Edwards, Gibson, Owen, & Wright (2013) as important in ensuring the successful integration of peer support workers in mental health teams. In keeping with this, Ross et al.’s (2018) study with NHS staff indicated that there should be more clarity around respective roles and more ‘joined-up working of volunteers alongside ward staff’ (p. 36). I discuss the issue of role boundaries in more detail below (section 2.6) since it is particularly relevant to this thesis. I now consider other staff concerns with involving volunteers.

2.4.4 Volunteers as ‘unprofessional’?

An important issue which emerges from the literature and was reflected in my findings, concerns staff worries that the ‘professional’ nature of their service may be compromised by the potentially lower quality of volunteer work and by volunteers’ perceived unreliability (Nesbit, Christensen, & Brudney, 2018). Ross et al. (2018) found that staff were concerned that they should not be reliant on volunteers since volunteers were not contracted and therefore not always available on demand. There was also concern about volunteers not having the right expertise. However, some respondents in Ross et al.’s (2018) study thought volunteers could be trained to widen their roles, for example to help feed patients, suggesting there was a range of attitudes towards volunteer involvement in that study. Staff views on volunteers are likely to be coloured by experience which may be influenced by aspects of organisational culture to which I now turn. I discuss the issue of volunteers being considered ‘unprofessional’ in the section on staff-volunteer boundaries below (section 2.6).

2.4.5 The role of organisational culture

Above I described the finding by McGarvey et al. (2019) that volunteer satisfaction depended partly on aspects of organisational culture such as volunteers being respected and trusted.

Although organisational culture does not seem to have been examined empirically in a UK-based

study, broad evidence from elsewhere suggests that it is likely to be important. For example, an Israeli study compared the experiences of social workers who worked with volunteers (n = 118) with those who did not (n = 69) (Caduri & Weiss-Gal, 2015). The findings showed that respondents who worked with volunteers were more likely than those who did not to rate their organisation's culture as being supportive of volunteers and to express positive opinions about volunteer roles. An Australian study of volunteers who helped patients at mealtimes on two hospital wards found that staff did not always welcome volunteers' insights into patients' needs (Ottrey et al., 2018). This initially generated tension, but following volunteer complaints to managers, staff were educated about the volunteer role and attitudes improved. In their recommendations, the authors suggested that volunteers should receive a handover with the nurse in charge at the start of their shifts in order to enhance volunteer-staff communication.

The importance of providing information for volunteers was also highlighted in a study of volunteers who supported patients with dementia admitted to an acute orthopaedic ward in an NHS hospital (McDonnell et al., 2014). Here, the role of a Dementia Nurse Specialist was considered by respondents (a mix of volunteers, staff and stakeholders from management, operational, strategic and clinical roles) to be crucial in providing expertise and guidance to volunteers and, therefore, to the success of their involvement.

In sum, although staff have understandable concerns about involving volunteers in health and care settings, evidence shows the importance of organisational culture in supporting volunteers to undertake their roles effectively alongside paid staff.

This section has provided an overview of 'formal' volunteering in the UK showing the depth and spread of volunteering across the population and in different economic sectors. I have highlighted some key issues in involving volunteers including motivation, satisfaction and barriers to volunteering, as well as challenges posed by social and demographic changes. In a focus on volunteering in health and care settings, I have described where volunteers are involved and given an indication of the wide range of roles they fulfil. I have also discussed the important issue of whether volunteers are complementary or substitutive when involved alongside paid health and care staff, showing that how this issue is perceived may depend on organisational culture rather than specifically on what volunteers do. I have described some staff concerns about

volunteer involvement and discussed aspects of organisational culture which are relevant to successful volunteer involvement. As I show in this thesis, all these issues are relevant to volunteering in hospices. I turn now to examine the volunteer role in this setting in more depth.

2.5 Understanding the hospice volunteer role

This section draws on a systematic review and thematic synthesis of qualitative studies with which I was previously involved (Burbeck, Candy, et al., 2014) which explored how the role of volunteers was understood at first hand by those involved. Since most of the included studies were published since 2004, they are helpful in illustrating the challenges in the volunteer role in the mature hospice movement. The synthesis used thematic synthesis (Thomas & Harden, 2008) to analyse the findings of the included studies. This involved inductively coding the relevant parts of each study, similar to undertaking qualitative analysis of primary data. This means that robust conclusions can be drawn from the available data since a structured method has been used to assess and combine study findings. In the following discussion I draw in relevant studies published more recently.

The review found twelve studies providing relevant qualitative data from interviews and focus groups, either from volunteers themselves (e.g. Andersson & Ohlen, 2005; Berry & Planalp, 2008; Watts, 2012) or from those receiving volunteer care (e.g. Weeks, MacQuarrie, & Bryanton, 2011). Six of the studies were based on experiences of volunteers in home care settings (Harris, 1991; Jack, Kirton, Birakurataki, & Merriman, 2011; Luijckx & Shols, 2009; McKee, Guirguis-Younger, MacLean, & Nadin, 2010; Sevigny et al., 2010; Weeks et al., 2008), three in volunteers involved in hospice buildings (Andersson & Ohlen, 2005; Field-Richards & Arthur, 2012; Watts, 2012), and three in mixed settings (Berry & Planalp, 2008; Finn, Miller, & Runnion, 1987; Guirguis-Younger & Grafanaki, 2008). Participants in seven studies were volunteers, in two they were patients or family members of patients who had received volunteer care, and in three studies respondents were from a mixed population or were volunteer coordinators. Seven studies were undertaken in North America, four in Europe (two in the UK) and one in Africa.

The review identified three theme 'clusters': the distinctness of the volunteer role (that is, is it different from that of staff?), the characteristics of the role, and volunteer experience of the role. In the following four sections I discuss the aspects of these which helped inspire this thesis using the headings: is the volunteer role distinct from that of staff?; the relationship with staff; the social nature of the role; and loss of informality in the role. I then turn to a consideration of the

context of death and dying, which arises in the studies included in the synthesis, but which was not a key theme. I discuss each topic in relation to aspects of the ideology of the hospice movement examined above and draw on other relevant literature as appropriate.

2.5.1 Is the volunteer role distinct from that of paid staff?

It could be argued that, in a truly egalitarian multi-disciplinary team, it would be hard to distinguish unpaid members of the team from paid members. However, it was clear from the included studies that the volunteer role was seen as distinct and separate from that of paid staff. One study author described it as '*complementary, not substitutive*' (Sevigny, 2010, p. 743), and others were keen to stress that the role does not overlap with that of staff. For example:

Most [participants] expressed a keen awareness of not to step outside their role, of not doing someone else's 'paid work', of not 'stepping on toes of the professionals' [volunteers] provide what no one on the health care team provides – they are companions to the dying – the possibility of infringing on the roles of others on palliative care team is minimal. (McKee et al., 2010, p. 167).

Other authors mention '*[volunteers being afraid to] cross over into the domain of the nurses*' (Andersson & Ohlen, 2005, p. 605). This suggests that, not only is the volunteer role seen as distinct from that of staff, but also that 'paid' or 'unpaid', and 'professional' or 'not professional' are important in the construction of the boundary between the two groups. I discuss this issue in detail with reference to my own data in Chapter 9.

Volunteers are seen as providing a qualitatively different kind of care to that provided by staff. One study reported volunteers being asked to stay on after their shift '*as one might ask of a friend but not of a professional....*' (Berry & Planalp, 2008, p. 461). This also indicates that volunteers are not thought of by patients' family members in the same way as staff. In another study, a bereaved spouse said:

"And I think, for Matthew, the fact of having somebody from outside, not just staff, is important. I think the staff that deal with you all the time, there is some humiliation in your situation that staff has to deal with at another level, his physical needs, so this is strictly someone to talk and be there, a friendly face, a kind face" (Weeks et al., 2008, p. 89).

Volunteers also appeared to occupy a 'middle ground' between patients and staff in roles such as 'go-between' or advocate. For example, volunteers "*(...) might notice something that hasn't been*

picked up by the nurses or something, indeed they might not have said to the nurses, something that they perhaps feel unable to talk about. So you know, we are able to pass stuff on if necessary" (participant in Field-Richards & Arthur, 2012, p. 629), and *'They [volunteers] also act as mediators and, at times, advocates for the patient'* (Sevigny et al., 2010, p. 741). This latter type of volunteer role has also been identified in research published since the review (Claxton-Oldfield & Blacklock, 2017; Vanderstichelen, Cohen, van Wesemael, Deliëns, & Chambaere et al., 2018).

Vanderstichelen et al. (2018) specifically identify the volunteer role in palliative care as liminal based on the fact that volunteers operate within both the professional sphere of professional staff and the family domain.

Another type of volunteer role identified in the included studies was that of a surrogate family member or friend (Field-Richards & Arthur, 2012; Harris et al., 1991; McKee et al., 2010; Weeks et al., 2008), for example, *"Knowing somebody else was aware of what the situation was. I think that was the biggest thing, other than the nurses in the hospital. It was just good. It was a replacement for family, because my family was all away"* (Weeks et al., p. 89).

However, the synthesis found a contradiction between this construction of the role as qualitatively different, and therefore, somehow 'special', with the finding that volunteers 'do what is needed'; in other words, they do *'the kinds of things no one else has time to do'* (McKee et al., 2010, p. 166). This could imply that volunteers perform tasks for which staff do not have time, which suggests that the volunteer role may not really be a distinct role as such, but rather a way of stretching available funding. It is not clear from the included studies in which participants talked about 'doing what is needed' what the tasks involved were, and whether they were part of paid staff's usual roles or not.

A similar tension is apparent in the broader volunteering literature. For example, in a wide-ranging review of organisational factors affecting volunteers across different types of institutions including hospices, Studer and von Schnurbein (2013) found that volunteers were considered, on one hand to be a 'unique resource' (p. 429), but on the other as laypersons or helpers. Volunteering has also been described as a 'hybrid strain of helping' (Ganesh & McAllum, 2012, p. 152), and as informal care in a structured setting (Bond, 1992). Although I did not observe these exact constructions of volunteering in my fieldwork, I saw others which also positioned volunteers as outside the professional boundary of care (for example, see Chapter 7).

It is possible that the 'distinctness' of the volunteer role may be an identity purposefully constructed by volunteers to validate and affirm their status within the hospice, particularly in response to an increasingly hierarchical organisational structure. It contrasts with volunteers' reports that they enjoy working in a team with staff (Andersson & Ohlen, 2005; Field-Richards & Arthur, 2012; Finn et al., 1987; Guirguis-Younger & Grafanaki, 2008). As one volunteer put it *"I very much appreciate that we work as a team . . . it takes some time to develop a relationship with the nursing staff, but once you have that, you are definitely a part of a team"* (Guirguis-Younger & Grafanaki, 2008, p. 20). This may indicate that volunteers see themselves as quasi-professionals rather than as a distinct group with an identifiable role. They may also feel that patients and families (and maybe the researchers who interviewed them) will take them seriously only if they appear to be 'professional-like'. The issue of the distinctness of the volunteer role arises more commonly in studies where volunteers themselves were respondents in contrast to studies where family members were respondents. Here volunteers were more likely to be seen as an additional or substitute family member or friend (Field-Richards & Arthur, 2012; Harris, 1991; McKee et al., 2010; Sevigny et al., 2010).

The distinctness or not of the volunteer role raises the issue of the existence of a boundary between staff and volunteers. I discuss research which has specifically examined this, together with Gieryn's (1983) proposals about how professional groups construct their identity, in section 2.6 I.

The discussion above of whether the volunteer role is distinct from that of staff suggests that there may be a tension between their identity as providing 'qualitatively different care' and the more prosaic 'filling in' of jobs not done by staff. Volunteer involvement has been seen simply as a way of helping hospices to reduce costs (Field & Johnson, 1993), while involving volunteers enabled the movement to extend hospice services and fully realise 'total care' (James, 1994, p. 105). The tension between volunteers as 'complementary not substitutive' and helping to save money can be seen in a Help the Hospices report on the involvement of volunteers (Help the Hospices, 2012). Here, volunteer care is described in terms of 'transcend[ing] the purely clinical' and training volunteers is important to 'enable the volunteer to manage the subtle tasks of hosting, managing and tailoring the hospice environment and shaping the organisation's resources to the patient needs' (p. 6; p. 8). The same document also states that the movement needs to 'identify clear boundaries for the volunteer working in a patient-facing role' (p. 4), and sees volunteers in terms of a resource, extending the care provided both in terms of skills

available and in terms of the numbers of people served (Help the Hospices, 2012). An earlier document provides a toolkit to help hospices calculate the financial value of their volunteers (Help the Hospices, 2007). As described above, the mature hospice movement operates within a marketised healthcare economy, competing for contracts with other providers. I argue that this creates an unresolved tension between the need to curb costs and involve volunteers in providing a different kind of care, and therefore forms part of the context – an outer frame – for understanding my data. In this thesis I explore the finding that ‘volunteer’ appears to be a distinct role from that of paid staff. I now consider the synthesis findings in relation to the volunteer-staff relationship.

2.5.2 Relationship with staff

It is clear from existing studies that the relationship between staff and volunteers is important in framing the volunteer role. For example, in some studies volunteers indicated that staff felt threatened by volunteers, such as *“Maybe they [the staff] felt a bit kind of threatened if you like, I don’t know why they would because I mean we’re not professional and you know we’re not nurses (...) I mean we’re only here to help you know (...) we’re not looking to take their jobs off them”* (volunteer in Field-Richards & Arthur, 2012, p. 629). From a study of volunteers in a hospice bereavement service Payne (2002) reports tensions between volunteers and paid staff, for example, over what counted as legitimate knowledge about bereavement, highlighting the difference between volunteers’ ‘lived experiences’ and staff’s ‘professional’ knowledge (Payne, 2002). Studies of peer support in mental health care settings highlight professional staff fears around diluting skills and the impact on care, peer workers’ feelings of not being accepted into the team, negative staff attitudes, and feelings of exclusion among peer workers (for example, Gillard, Edwards, Gibson, Owen, & Wright, 2013; Walker & Bryant, 2013).

There is also evidence that staff ‘control’ the volunteer role, for example, by restricting access to confidential patient information which volunteers considered they needed. For example, Andersson and Ohlen (2005) report volunteer concerns that they did not have sufficient information about patients to ascertain whether an activity was appropriate, such as whether a patient could be safely taken for a walk. Emphasising the need for information-sharing to improve teamwork, they reported a participant saying *“As a volunteer I can easily feel left out since I do not understand much of what’s going on in the work”* (p. 605). Other authors report issues around patient confidentiality (Finn et al., 1987) and safety (Field-Richards & Arthur, 2012). The role of patient information was important in understanding the boundary between staff and volunteers in my data, and is explored in Chapters 5, 6 and 7 (sections 5.3, 5.4, 6.4.1 and 7.2.2).

Another study described how volunteers were frustrated with reporting arrangements that acted to limit their role, *“Several volunteers wanted to function as counselors [sic] and to communicate directly with the nurse rather than to work with the social worker. They perceived the nurse as having greater authority and power over patient care plans than the social worker”* (Finn et al., 1987, p. 171). This may show how these volunteers understood that there was a hierarchy in place and how to ‘manipulate’ it. However, staff were also supportive of volunteers, *“If there were things that I thought I wanted to do for the clients, staff would say go ahead, as long as it is safe. ... It is a very open and supportive environment. If I said I wanted to try something, the staff would go to great lengths to help me get it started”* (Andersson & Ohlen, 2005, p. 18).

As argued above, the relationship with staff is therefore very important in constructing the volunteer role, suggesting that the boundary between paid staff and volunteers is key. A survey of volunteers in several English hospices (covering a range of volunteer roles including administrative and care-related roles) identified this boundary as problematic (Hoad, 1991). In particular, the study concluded that lack of clarity around the boundary – for example, over access to confidential patient information – could lead to tension between volunteers and staff (Hoad, 1991). I discuss theoretical approaches to the concept of boundaries and their explanatory power in understanding organisational roles below (section 2.6).

2.5.3 The social nature of the role

Participants in the studies included in the synthesis characterised their role largely in terms of its social nature rather than in terms of the tasks they undertook (Andersson & Ohlen, 2005; Berry & Planalp, 2008; Field-Richards & Arthur, 2012; Finn et al., 1987; Luijkx & Shols, 2009; McKee et al., 2010; Seigny et al., 2010; Watts, 2012; Weeks et al., 2008). This extended to what they had *expected* of the role beforehand, with one participant saying that they had anticipated *“more opportunities to meet them [patients] in some kind of human relationship”* (Andersson & Ohlen, 2005, p. 605). The social nature of the role was apparent in specific aspects of the volunteer role including providing support (Finn et al., 1987; Luijkx & Shols, 2009; Weeks et al., 2008) and in social ‘acts’, described as ‘just being there’ (Guirguis-Younger & Grafanaki, 2008; Finn et al., 1987; Harris, 1991; McKee et al., 2010; Seigny et al., 2010; Weeks et al., 2008) or ‘just listening’ (Berry & Planalp, 2008; Field-Richards & Arthur, 2012; McKee et al., 2010; Weeks et al., 2008). ‘Being there’ was also identified as a key aspect of the volunteer role in a more recent study by Vanderstichelen et al. (2018).

While the social nature of the volunteer role reported by these studies largely fits with the specific tasks most commonly undertaken by volunteers (Burbeck, Low, et al., 2014) outlined in Chapter 1 (section 1.6), it shows how study participants saw the role in terms of its broader *meaning* to them and not simply as a role based on specified tasks. This demonstrates how qualitative research approaches can illuminate a 'reality' beyond a simple gathering of statistical data and focus on the 'insider' view of a social context (Avis, 2005).

2.5.4 Loss of informality in the role

In the overview of the history of the hospice movement above I discussed how the movement became increasingly bureaucratised. This aspect could also be seen in the findings of the qualitative synthesis which identified tension between the 'traditionally' flexible volunteer role and the increasing need for statutory-led formalisation of the role. In three studies, volunteers made a connection between the unpaid nature of their role and their perception of the role as informal (Field-Richards & Arthur, 2012; Sevigny et al., 2010; Watts, 2012), for example which *'attracted them [i.e. volunteers] to volunteer initially'* (Field-Richards & Arthur, 2012, p. 628). Informality was also mentioned as something that, for some volunteers, was slowly being eroded as an increasingly structured working environment was being introduced (Field-Richards & Arthur, 2012; Watts, 2012). The introduction of professional human resource practices (such as job descriptions, interviews and appraisals) appears to have formalised the role: *"It all has got so formal somehow and maybe we matter less because of that"* (volunteer in Watts, 2012, p. 112). Within the hospice movement, there have been fears for some time that increased professionalisation of volunteer practices may lead to an erosion of the qualitatively different nature of the role in palliative care (Guirguis-Younger et al., 2005).

These findings are supported by Morris, Payne, Ockenden, and Hill (2017) who undertook a UK-based mixed methods study incorporating interviews with over 200 volunteers, staff and patients and relatives, a narrative literature review and a survey of volunteer managers. The authors highlight tension between the traditional flexibility of the volunteer role and increasingly professionalised nature of volunteer management with volunteers in well-defined roles within hierarchical systems resulting from the regulatory framework within which hospices now operate (p. 7).

2.5.5 The context of death and dying

The issue of how volunteers cope with the emotional aspects of being involved in a setting where death and dying are present also arises in the published qualitative literature. Some studies found

that volunteers consider being emotionally resilient to be important. For example, *“It’s not easy, but you need to detach a little bit. You cannot carry every death with you”* (volunteer in Guirguis-Younger & Grafanaki, 2008, p. 20). In other studies, authors called for volunteers to be trained to deal with death and dying (for example, Finn et al., 1987) while others found that volunteers avoided the topic with patients (Andersson & Ohlen, 2005). A study of coping skills among palliative care volunteers (not part of the earlier synthesis as it does not provide data specifically on the volunteer role), suggests that volunteers use a range of coping techniques (Brown, 2011a). These include emotion-focused coping (talking with others, pet therapy, avoidance, going to funerals, religious beliefs), problem-focused coping (talking with others, seeking assistance), making meaning through appraisal (religious beliefs, views about death, benefit finding), and physical activities (walking, dog walking, breathing techniques).

In this section I have focused on how the role of volunteers with patient- and family-facing roles in hospices is understood by those with first-hand experience based on a systematic review and qualitative data synthesis with which I was previously involved (Burbeck, Candy, et al., 2014). I highlighted tensions in the role, such as whether it is complementary or substitutive, as well as changes to the role as the hospice movement has developed, notably, a perceived reduction in informality and flexibility, both key values of volunteering (Merrell, 2000).

My discussion in this section also demonstrates how the volunteer role is positioned in relation to other roles, namely those of staff, and points to the existence of boundaries within which the role is contained. One of the most of important of these is the staff-volunteer boundary, and I now consider literature which has specifically addressed this, together with theoretical approaches to studying boundaries between organisational roles.

2.6 Focus on the staff-volunteer boundary

Above I discussed the extent to which the volunteer role is distinct from that of paid staff and how the relationship with staff produces a boundary which is potentially problematic (Hoad, 1991). This section considers literature which specifically addresses this issue. Given the paucity of data in palliative care settings, I have included studies in other health and social care sectors since the broad issues are similar.

In an interview-based study of volunteers supporting community-based care of older adults in fourteen different schemes (including advocacy, befriending and sitting services), Hoad (2002) concluded that boundaries between volunteers and staff were often subject to processes of negotiation, rather than being 'fixed'. While volunteers did not try to take over professional roles, the tasks they performed depended on individual volunteer characteristics. This highlights two points. First, in contrast with how the hospice volunteers above saw their roles, the boundaries of the volunteer role are thought of in terms of the specific tasks volunteers are permitted to do. These may be decided at an organisational level and 'scripted', for example, in a volunteer 'job' description. Second, Hoad (2002) makes the valuable point that, unlike paid staff, boundaries around what volunteers do are not necessarily related to the skills of the volunteer, who may be well qualified for the tasks in question.

A further problem is raised when volunteers offer their professional skills in the same arena as paid staff with the same skills. This was noted by Payne (2002) in her study of volunteers in hospice bereavement services in New Zealand, and also by Merrell (2000) in a study of volunteers in a well-woman clinic. Merrell noted considerable ambiguity in the volunteer role, for example, about whether volunteers should give advice to clients or just make 'suggestions'. It raises the question about whether volunteering in organisations which also employ paid staff inevitably leads to ambiguous boundaries between the two groups since the values of volunteering are contradictory with that of paid work, particularly within the marketised UK health system (Merrell, 2000). I draw on my data to examine the issue of volunteers offering their professional skills in Chapter 7.

Overgaard et al. (2015) compared boundaries between volunteers and staff in hospices in Denmark and Australia. Volunteers in Denmark were not allowed to undertake care work, while those in Australia were. The authors argued that this difference was based on the socio-political system within each country. Denmark had a social democratic state system where the care-providing profession of nursing had a monopoly on care work. However, in Australia, which had a liberal welfare state, the concern was not with professional groupings, but with risk: as long as the perceived risk to patients was minimised and deemed acceptable, volunteers were permitted to undertake care work. Although, these conclusions can be criticised for trying to find causal explanations with little evidence, it shows the importance of considering the wider context in which care is being provided, in this case, the culture of different healthcare systems and the influence of the political framework. In the UK, which has a liberal welfare state system, care work

is the least common activity for hospice volunteers (Burbeck, Low, et al., 2014) as my data demonstrate (Chapter 7).

As well as considering boundaries in terms of the tasks different groups of actors perform, other research has examined boundaries in terms of the dynamics of how different roles are negotiated between actor groups *in situ*. In an ethnographic study of an intensive care unit (ICU), Conn et al. (2016) identified how the different professional groups involved in patient care sought to establish, control and protect their roles. Conn et al. (2016) employed Gieryn's (1983) concept of 'boundary work' (my emphasis) to explain what was going on. This refers to rhetorical and discursive practices involved in creating professional autonomy. Gieryn (1983) identified that scientists used these practices to construct a professional boundary to distinguish themselves from non-scientists, for example, by attributing particular characteristics to the institution of science, thus legitimising 'scientist' as a professional category. Conn et al. (2016) also noted how the different professional groups within the ICU communicated with each other using 'boundary objects' (Star & Griesemer, 1989), such as protocols and checklists, which provided shared points of contact.

Using Gieryn's concept of boundary work in terms of 'demarcation work', that is, marking out the boundary between one role and another, van Bochove, Tonkens, Verplanke, & Roggeveen (2018) compared professional staff with volunteers across four social care settings (nursing homes, day-care for people with intellectual disabilities, community centres and children's play grounds). Based on interviews and observations, they identified examples of demarcation practices used by volunteers and professional staff from which they identified three 'boundary markers': knowledge and skills; status and authority; and predictability and reliability (p. 8). From this, volunteers were typically characterised as 'unskilled, unauthoritative and unreliable' (p. 8). However, the authors also identified another kind of boundary work being performed, which they termed 'welcoming work'. This occurred when professionals recognised the competencies of *specific* volunteers and *welcomed* them 'into the professional domain' (p. 11). This happened most often when professional staff were busy. I use this concept to help explain some of my data, in particular, in Chapters 7 and 8.

In this section I have explored the boundary between volunteers and paid staff, including research in care-related areas other than hospices. Through this literature, I identified that this boundary is concerned not just with what volunteers are, and are not allowed to do, but also with the processes of negotiation which occur *in practice*. From this negotiation I introduced Gieryn's (1983) concept of 'boundary work'. Such work is subdivided into 'demarcation work' and 'welcoming work'. I have also identified the potential for tension between volunteers offering professional skills and paid staff. I draw on these ideas in interpreting my data later in this thesis.

Above, I introduced the idea of the importance of the life-death boundary in the management of death and dying, so turn now to consider theoretical ideas about boundaries and how they are relevant to the management of death.

2.7 Boundaries: their role in the management of death

Zerubavel (1991/1993), drawing on Mary Douglas, suggests that social meaning is constructed through the concept of boundaries: 'to define something is to mark its boundaries, to surround it with a *mental fence* that separates it from everything else' (Zerubavel, 1991/1993, p. 2, emphasis added). I therefore begin with the seminal ideas of Mary Douglas which underpin this thesis. I then argue how the hospice can be constructed as a liminal place between life and death.

2.7.1 Mary Douglas: danger in pollution

The anthropologist Mary Douglas (1966/2002) demonstrated how the classification of 'matter', by which she meant any 'thing' material or not, creates a set of ordered relations which has culturally symbolic meanings. Douglas (1966/2002) gives the example of the classification of items as edible or otherwise in the dietary rules set out in Leviticus. All such classificatory schemes produce anomalies or ambiguous – 'matter out of place' (p. 203) – some of which are polluting and, therefore, threaten to create disorder within society by defiling the set of ordered relations. 'Dangerous' matter – dirt – therefore has to be dealt with. Douglas used these ideas to explain taboo and ritualistic responses to 'dirt' which are enacted in order to 'purify' what has become 'polluted' (p. 49). The key point is that these are symbolic and culturally embedded. For example, menstrual blood is regarded as polluting in some orthodox Jewish societies and women therefore take a ritual bath at the end of their menses in order symbolically to re-enter society. Rituals therefore control 'danger' by restoring order thus avoiding chaos. Funeral rites are another example, 'safely' incorporating the person who has died into the category 'ancestor'.

Sometimes, matter simply does not fit a category within a classificatory scheme. Such anomalies cause 'cognitive discomfort' (1966/2002, p. xi) which can seem threatening because of their potential to cause disorder (p. xi). Douglas distinguishes anomalous matter, that which does not fit any category, from ambiguous matter, that which can belong in more than one category. Ambiguous matter can be dealt with by simply allocating it to a category and then dealing with it accordingly. Anomalous matter could be dealt with in a number of ways to prevent it from 'polluting' society, threatening chaos. It could simply be removed (such as by killing it or throwing it away) or just avoided. I use the idea of anomalous and ambiguous matter to explain paid staff's treatment of the 'professional' volunteers in Chapter 7.

As death is one of the ways 'nature' threatens 'culture' (Walter, 1991), these ideas help in understanding the 'dangerousness' of the life-death boundary. For example, above I set out how producing a 'good death' is key in hospice ideology. This is death which is 'orderly' since 'bad death' is associated with disorganisation and chaos, threatening individual and social stability (Howarth, 2007, p. 175). Examples include deaths which are unanticipated, such as, suicide or death from accident, or 'unnatural', such as the death of a younger adult or child (Komaromy & Hockey, 2001). Preventing chaos from death is fundamental to the hospice 'project' and is also seen in the volunteer role in some settings, as I show in Chapters 5 and 8.

One way the hospice provided structure was through food practices which, as Douglas shows, are culturally produced (Douglas & Nicod, 1974; Douglas, 1975). Bearing in mind that her analysis was undertaken over forty years ago, Douglas shows that British food practices are structured around three meals a day sequenced so that 'breakfast' is followed by 'lunch' then 'dinner'. Each meal is distinguished by the food items served and the order in which they are eaten, so that, for example, savoury items typically come before sweet ones. The food making up a 'meal' also comprises contrasting elements, such as meat and vegetables, and contrasting textures, such as, 'wet' gravy or custard with 'dry' meat or pie. These structures therefore create the concept of the 'proper' meal, that is, one which follows the rules: eating cornflakes for lunch would not be a 'proper' meal. Douglas argues that these patterns show how food practices are a ritual activity, providing a cultural resource. Douglas also argues that there is a commensal cycle with the Christmas feast at its heart, and Sunday lunch as the weekly 'climax' (Douglas, 1975, p. 257). I use these ideas in Chapters 5 and 6 to show how the hospice meal routines, which were maintained regardless of how relevant they were to a patient's state of health, helped to control the potential for death and dying to cause chaos and thus to produce 'living'. Through such practices, the

hospice manages the potentially messy transition from life to death, and thus can be seen as a liminal place (Froggatt, 1997; Hockey, 1990). An important feature of liminal places is the role of the 'expert' as I explain in the next section.

2.7.2 Liminality: experts and *communitas*

Liminality is a theoretical construct developed by Turner (1969/1974) from the anthropologist van Gennep's (1960/1977) *rites de passage* model of the use of ritual to create or mark change. The term derives from *limen* meaning threshold, hence its use to denote moving across a boundary from one state to another. The model involves three stages: separation, transition and (re-) incorporation. Examples include changes in status, such as getting married or gaining majority, or in life-stage, such as birth and death.

Drawing on van Gennep, Douglas (1966/2002) suggests that the transitional, middle, phase is potentially 'dangerous' since *liminars* are neither in the original status nor the new one (p. 119). As 'betwixt-and-between' two domains (Turner, 1967, p. 71), *liminars* are characteristically ambiguous and potentially unstable. To transfer from one status to the next 'safely' may involve the performance of rituals ensuring that the *liminar* is reincorporated 'properly' into society with their new status and, possibly, with new responsibilities and powers (Beech, 2011). For example, funeral rites ensure that the person who has died is 'safely' transferred to a new status of 'ancestor'.

Froggatt (1997) argues that, in managing the transition between life and death, the hospice is a liminal place, and that the characteristics of liminality can be applied to aspects of hospice ideology. For example, the liminal concept of transition is similar to hospice ideology of dying as a journey, and absence of status corresponds to the idea of the hospice community as family. Van Gennep (1960) noted that tribal elders, as masters of ceremony, supervised those who were experiencing liminality. Therefore, healthcare professionals in hospices can be seen as masters of ceremony or ritual specialists (Froggatt, 2005). Komaromy (2005), in her ethnographic study of death in care homes, observed that when a resident died, the management of death was taken over by 'experts', that is, by the more highly trained, higher status, staff. Using Douglas' arguments about the use of classificatory schemes to impose order on chaos, and viewing the hospice as a liminal space, the medicalisation and therefore professionalisation of the care of dying people means that death is handled more and more by 'experts'. As I will show in this thesis, this had implications for volunteers who do not have 'professional' status.

An effect of liminality is that any pre-existing social structure becomes flattened so that hierarchical relationships between social actors are reduced or even eliminated (Turner, 1969/1974, p. 82). He calls this '*communitas*' and suggests that *communitas* could be identified in the literature and behaviour of 'alternative' groups in the 1960s, such as the 'beat' generation and hippies. Froggatt (1997) suggests the absence of rank in the hospice multi-disciplinary team equates to such a flattened hierarchy. The concept of '*communitas*' describes the type of community the original hospice ethos of 'total care' aimed to establish (Froggatt, 1997; du Boulay and Rankin, 2007). (It should be noted that Turner (1969/1974) deliberately used the term *communitas* rather than community.) However, as I describe above, the hospice movement could not exist in a vacuum, and as a result became institutionalised and bureaucratised. Indeed, Punch (1974) warns that an attempt to establish *communitas* is likely to fail partly because interacting with wider society is unavoidable.

In this section I have explained theoretical approaches to understanding the role of boundaries, particularly, the life-death boundary which is key to understanding the volunteer role. I have introduced the idea of the hospice as a liminal place managing this boundary. As I noted above, the life-death boundary is maintained in society through the influence of the medical model and this contrasts with the hospice movement's ideology of 'living until you die' (Hockey, 1990). As I will show in this thesis, a large part of the hospice volunteer role is concerned with supporting the hospice in its endeavour to help patients 'to live until they die'. In other words, volunteers support the hospice to produce 'living' in the face of dying (see Chapters 5, 6 and 8). The production of 'living' requires the hospice to manage a 'performance' and I now discuss Goffman's (1959/1990) ideas about how this is achieved.

2.8 Disconnect between ideology and practice: dramaturgy

Promoting 'living' in the face of dying requires both the hospice and its personnel to produce a convincing performance. As I have suggested above, one example of this was in the way that patients were given food based on a 'traditional' three-meals-a-day pattern, which, as I show in Chapters 5 and 6, was sometimes 'resisted'. Food practices were therefore ritualistic, and the 'script' for them was based in a cultural expression of 'living' through hospitality. Similar 'scripts' were apparent in written information given to patients (described in Chapters 5 and 8) and also

existed for the 'actors' involved in this performance. According to Goffman (1959/1990), interactions are performances which are socially determined and which may be structured in culturally acceptable and formalised ways, that is, as rituals. Goffman is associated with symbolic interactionism, which is concerned with people's everyday lives and how they create meaning and order out of everyday interactions. He was particularly concerned with the analysis of actions in public places. I employed his notion of dramaturgy to help me to recognise what was happening with the volunteer role in the situations which I observed. Symbolic interactionism is particularly relevant to the study of socially constructed organisational roles, such as that of volunteer.

Goffman (1959/1990) employs a theatrical metaphor to throw light on the meaning of social behaviour, in particular, on the *management* of performances. He outlines six 'dramaturgical' principles: the performance, the team, the region, discrepant roles, communication out of character and impression management (1959; Manning, 1992). Goffman argues that social actors give a performance based on the stereotyped expectations of the given situation. This may involve a team of people contributing to the performance, and must be 'convincing', and can also include the 'audience'. In the hospice, teams therefore include staff, volunteers, patients and relatives.

Performances involve not only the actors' behaviour, but also the 'set' and the 'props'. Here, Goffman distinguishes between 'front' regions and 'back' regions. Continuing the theatrical metaphor, these correspond to the front stage where the performance is given which is viewed by the audience, and the back stage where the performance is prepared and where the actors relax out of view of the audience. For example, nurses perform their scripted caring roles in the front space of a ward, but may act differently in the back space of a staff room. Comparing the two may help to illuminate what is really happening. The impression being produced is managed on the front stage but may be deliberately contradicted back stage (Goffman, 1959/1990). I explore the social meaning of the hospice spaces and how they were presented in Chapter 4.

Discrepant roles may emerge which can help to explain role ambiguity. For example, a volunteer could be performer in one situation but audience in another. Similarly, communication out of character occurs when actors disclose information which 'reveals' the performance. Finally, impression management involves various defensive practices used by the performers to 'save the show'. These could include team members covering up when the script is disrupted – for example, if a patient dies unexpectedly – and maintaining the performance until the audience has left. It may also include collusion on the part of the audience by ignoring discrepancies in the

performance, or covering them up, for example, by laughing (Manning, 1992). Thus, Goffman 'downplays the self in favour of the situation' so that there is no 'real' self but a set of masks and 'performances', tailored to different audiences, which Goffman called 'impression management' (Sandstrom, Martin & Fine, 2001, pp. 220-221).

However, Goffman is not suggesting that people are automatons following a particular 'script'. While he is suggesting that we use 'masks' to manipulate social interactions, and that these masks, the roles they represent and the performances we give, are socially produced (Manning, 1992), he recognises both people's individual agency and that they have a 'real' self behind the mask (Goffman, 1974/1986) albeit one which remains social:

The license [sic] of departure from the prescribed role is itself something that varies quite remarkably, depending on the 'formality' of the occasion There is a relation between persons and role. But the relationship answers to the interactive system – to the frame – in which the role is performed and the self of the performer is glimpsed. Self, then, is not an entity half-concealed behind events, but a changeable formula for managing oneself during them (p. 573).

I use Goffman's ideas to show how the hospice staged and maintained a performance of 'living' and to explain the volunteer role in this performance in Chapters 5, 6 and 8. This approach has been utilised by other ethnographers in death studies, for example, Komaromy's study of the death of care home residents (2005) and Howarth's study of a firm of funeral directors (1996). The former showed how staff 'produced' a 'good' death through giving a convincing performance when 'managing' the death of a resident. Howarth showed how funeral directors 'civilise' the horror of death.

2.9 Summary

In this chapter I have set out the development of the hospice movement as a counter movement based on an ideological critique of the medicalisation of death and as a response to the poor provision of care for dying people, effectively 'humanising' care (Abel, 1986, p. 81). I have outlined hospice ideology, a key aspect of which was an egalitarian approach to providing care embodied by the multi-disciplinary team and a less hierarchical approach to care provision than in other healthcare settings. However, this ideology has become compromised as the movement matured becoming increasingly bureaucratised and institutionalised. Increasing

professionalisation of healthcare roles in general and, thereby, a re-professionalisation of care for dying people, made it difficult for the movement to sustain the original ethos. I have suggested that this may have impacted on volunteers, who were central in this. Casting the hospice as heterotopic helps to understand the ambiguous nature of the institution which seeks to produce 'living' in the face of dying. I argue that this contradiction produces the tensions which construct the volunteer role. I explored the extent to which these are apparent in the extant literature on volunteers in hospices. I then turned to how one issue in particular, the boundary between paid staff and volunteers, has been addressed in the wider arena of care services, focusing on the theoretical approach of Gieryn (1983). I then discussed how the life-death boundary may be socially constructed, using the ideas of Mary Douglas, and how casting the hospice as a site of liminality may help to shed light on the contemporary construction of the role of volunteers using ideas about ritual experts and *communitas*. I then discussed Goffman's dramaturgy which helped me to explain how the hospice staged a performance of 'living'.

Chapter 3. Methodology and methods

I explained in Chapter 1 how my initial interest in the volunteer role stemmed from my own experiences as a volunteer, and how this led me to realise that the term ‘volunteer’ appeared to have a social meaning independent of the individuals filling the role. In Chapter 2 I described my later research work on *hospice* volunteers which highlighted the existence of conflicting meanings of the role in this milieu (Burbeck, Candy, et al., 2014). I considered that there was more to be uncovered, and that the tensions my colleagues and I had identified could be resolved by digging deeper. Therefore, I wanted to find out how the volunteer role ‘worked’ in practice, in particular in relation to the roles of paid staff and how the meaning of ‘volunteer’ was constructed through actions and behaviour. As I explained in Chapter 1 a social constructionist viewpoint fitted epistemologically with what I wanted to know. Therefore, my overarching research question for this project was: how is the volunteer role in a hospice setting constructed? Since social constructions are generated and reproduced within sociocultural settings (Berger & Luckman, 1966), I posed five sub-questions which I identified from the tensions between the hospice volunteer role and the contemporary hospice movement in Chapter 2:

- 1) Is the volunteer role distinct from that of (paid) staff?
- 2) How does the relationship between staff and volunteers generate and sustain the role?
- 3) How does the hospice as an institution construct the role?
- 4) How does the context of death and dying shape the role?

Since research should inform practice, I asked a fifth question:

- 5) How can this understanding of the volunteer role inform practice?

The research discussed in Chapter 2 was based on data from interviews and focus groups. While such data are valuable, for example, to aid understanding about volunteering from a phenomenological standpoint or for exploring discursive practices (Willig, 2012), observational methods allow the possibility to see what is happening within the immediate everyday context of participants (K.M. DeWalt & DeWalt, 2011) and to capture the ‘social meanings’ of what is going on (Brewer, 2000, p. 6). Despite having previously researched in the area of hospice care, my research had been largely desk-based so I had little knowledge of everyday hospice culture. Following Howarth (1996), who also had little prior working knowledge of her object of study, a funeral director’s business, I chose ethnography as the best strategy to gain an ‘insider’

perspective of the volunteer role. Ethnographic methods have been previously used in the sensitive field of palliative care research (Seymour, 2007), for example, Glaser & Strauss (1965), Lawton (2000) and Sudnow (1967).

This chapter describes my research approach. It is in six parts: in the first I discuss my methodological positioning; I then discuss ethnography and how I navigated the issues that the approach throws up. In the third part I describe the research context, how I chose the fieldwork sites, gained access, and approached ethical issues. In the fourth part, I describe the fieldwork sites, the settings within them in which I researched, and the research participants. The fifth part discusses my data collection methods, and finally I describe the analysis process.

3.1 A social constructionist methodology

Here I explain why I took a social constructionist approach to my object of study, the volunteer role in hospices. This view assumes that the object of study is experienced, understood and named via learnt social and cultural processes. It focuses on how the norms and expectations about the object of study operate within specific sociocultural settings. However, the ontological status of 'social reality' within constructionist approaches varies between proponents, with some taking the 'extreme' *relativist* view that all social reality is constructed (for example, Gergen, 1994), while others take a *realist* view that social phenomena exist beyond people's imaginations (Delanty & Strydom, 2003). I took a position between these extremes. If organisational roles are socially constructed, it does not necessarily mean that there is no 'reality'. Therefore, while I cast the object of my study, the volunteer role, as socially constructed, I acknowledged that the social processes creating the role existed independently of my, or my participants', constructions. This meant that I recognised that the wider sociocultural context and the structures resulting from this played a significant role in constructing the volunteer role (and were likely to have contributed to the range of conflicting meanings of 'volunteer' identified in Chapter 2). Such context can comprise social, cultural, economic and material structures, for example, how death and dying are viewed and managed. Therefore, I describe my approach to 'reality' as a 'moderate' social constructionist one (Willig, 2012).

Within a constructionist approach I drew on the notion of discourse in identifying actors' use of discursive resources (Hardy, Palmer & Philips, 2000). A discourse is, not just the content of communication (Schirato, Danaher & Webb, 2012), but also a 'system of representation which regulates the meanings which can and cannot be produced' (Smith, 1998, p. 254). Discourses

therefore provide a resource to allow actors to position either themselves or others. These discursive resources were important in showing how volunteers were located by other actor groups.

Having chosen an ethnographic approach as the most appropriate method to help me understand the volunteers' 'roles, actions and behaviours' (Walshe, C., Ewing, G., & Griffiths, J., 2012, p. 1048), I engaged with the debates within ethnography about how the method makes 'truth' claims. Many ethnographers resolve these arguments by claiming a modified 'realist' position (van Maanen, 2011), for example, Hammersley's 'subtle realism' (1988; 1990) and Thomas's 'critical realism' (1993). In the next section I explain how my 'moderate' social constructionist position can be aligned with such a modified 'realist' position. I begin with an explanation of how ethnographic methods raise these issues.

3.2 An ethnographic approach

Ethnography is the 'peculiar practice of representing the social reality of others through the analysis of one's own experiences in the world of these others' (van Maanen, 2011, p. xiii). Its complex history rooted in anthropology and reflecting ongoing ontological and epistemological debates within the social sciences (Seymour, 2007; see Delanty & Strydom (2003) regarding social science debates), means there is little consensus about precisely what constitutes 'ethnography'. Hammersley and Atkinson (2007) suggest that the principal features include:

- Studying people at first hand in their everyday context in order to focus on their perspectives;
- Using a range of data collection methods, such as participant observation, relatively informal conversations between the researcher and those s/he is studying, and documentary evidence;
- An approach to data collection that is unstructured. Data are not collected based on a fixed schedule or pre-determined categories although the researcher has an idea of what the focus of the research is but may not be clear what the research is about until well on into the process.

These methods raise the question of how to present a 'true' picture of someone *else's* social world. Addressing this involves dealing with two related problems: first, how the product of

ethnography, the ethnographic text, represents 'reality'; and second, how the quality of the research findings can be judged (that is, in positivist terms, their validity, reliability and generalisability). Following the postmodern turn in the late twentieth century these issues became known in ethnography as the 'double crisis' of representation and legitimisation (Denzin & Lincoln, 1998; Brewer, 2000). Postmodernism refers to the breakdown in the 'meta-narrative' whereby over-arching 'narratives' have dissolved, leaving a multiplicity of narratives and potentially endless relativity with no absolute truth (Smith, 1998) and thus multiple 'realities'.

This paradigm is particularly problematic for ethnography. The reliance on the researcher as research instrument to collect, analyse and interpret data (Coffey, 1999) raises issues about how the method claims to produce a 'true' account of 'reality'. For example, at the heart of participant observation, which was my main data collection method, is the problem of the extent to which what the researcher 'sees' is affected by that researcher's inevitable interaction with the field. I return to this discussion in section 3.5.1 where I describe how I positioned myself on the continuum between 'observing' and 'participating'. I now discuss how the issue of what counts as 'truth' has been approached by ethnographers.

3.2.1 The problem of 'truth' in ethnography

The crisis of representation concerned the status of 'thick description' as a way to provide an accurate account of reality. Thick description refers to a detailed description of the circumstances, meanings, intentions, strategies and motivations that characterised an episode in the field (Hammersley, 2008), thereby giving an 'insider' account. The term is associated with Geertz, although was in turn borrowed from the philosopher Gilbert Ryle (Geertz, 1973) and is a cornerstone of the ethnographic method. However, it was easily criticised as theoretically naïve since it produced accounts which were incomplete or simply cultural descriptions no different to those produced by a lay person (Brewer, 2000; Hammersley 1990), for example, Malinowski's (1922) *Argonauts of the Western Pacific*. In other words, when used without acknowledgement of the values brought by the researcher or admission that there may be other interpretations, thick description produces 'realist tales' based on an 'assumed Doctrine of Immaculate Perception' (van Maanen, 2011, p. 73). Alongside this, postmodern relativism meant that the quality of ethnography was difficult to judge, creating a crisis of legitimation (Brewer, 2000). In other words, on what grounds could ethnography claim to produce legitimate accounts?

The roots of these crises lay in the subject-object problem or methodological dualism which characterised the academic discipline of sociology from the 1920s onwards (Gouldner, 1970). This

acknowledged that the assumption of positivist science that the subjects and objects of study could be separated, thus producing the objectivity necessary to 'do' science, was endangered by the interaction between those studied and the researcher (Gouldner, 1970). In response Gouldner proposed a 'Reflexive Sociology' (1970, p. 267), in other words, a sociology able to account for its own production (Armstrong, 2009).

Postmodern ethnographers also turned to reflexivity as a solution to the two crises (Brewer, 2000). Although something of a 'slippery' term (Foley, 2002, p. 473), the essence of reflexivity is that researchers acknowledge they are part of the 'setting, context and culture he or she is trying to understand and represent' (Brewer, 2000, p. 127). This is achieved by researchers reflecting on the research process and their place in it, including challenging the assumptions they may have made, their theoretical stance and what they personally bring to the research process from initial concept through to final text (Hubbard, Backett-Milburn, & Kemmer, 2001).

Since I planned to use participant observation as my main method, the issues of accessing and then representing 'reality' were of particular concern. How would readers judge my interpretation? With these problems in mind I drew on Brewer's (2000) blueprint for reflexivity, the 'ethnographic imagination'. This provides a systematic approach to articulating the decisions made at all stages of the research process. The name refers to the 'imaginative leap' the reader of ethnographic products makes to recognise the authority of ethnographic data (Brewer, 2000, p. 51).⁹

I describe Brewer's approach next.

3.2.2 Reflexivity: the 'ethnographic imagination'

The approach is based on three 'dimensions' (Brewer, 2000, p. 53). These are epistemological assumptions derived from reflection rather than from systematic empirical enquiry, and answer the question 'What and how can we know?' (Willig, 2012, pp. 9-10). The dimensions (adapted from Brewer, 2000, p. 53) are:

⁹ The term 'ethnographic imagination' had previously been used by Atkinson (1990) to 'describe the artful and creative rhetorical abilities' of ethnographers (Brewer, 2000, p. 51).

- The belief that the data collected (such as field notes) can reliably represent a social world as long as the ethnographer has been reflexive and thereby established his or her integrity and the authority of the data, even though the social world cannot be completely described in the confines of an ethnographic text;
- The belief that small-scale, micro events in everyday life have at least common features with the broader social world, such that general processes permeate down to and are in part reproduced at the level of people's everyday lives, and thus illustrate features of broader social processes provided the ethnographer sets out the ground on which these generalisations are made;
- The belief that people make sense of their everyday lives, although their accounts should not be taken at face value.

Based on these dimensions, Brewer's (2000) guidelines for reflexive practice, which I adopted for my study, include:

- Establishing the wider relevance of the setting and the topic. For my study this meant considering the extent to which the fieldwork sites and the volunteers I followed were representative of similar settings;
- Identifying the features of the topic being addressed (and those not being addressed) in order to be explicit about why I chose some aspects to research above others;
- Identifying my theoretical framework including the broader values and commitments I brought;
- Establishing my integrity as a researcher by outlining the grounds on which I am making knowledge claims, including describing specific aspects of the fieldwork (such as time in the field, how access was negotiated and the extent of rapport developed with respondents); my background in relation to the setting and my experiences during the research, including any constraints; and the strengths and weaknesses of the research design;
- Establishing the authority of the data by outlining any problems that arose during fieldwork; describing how the analytical framework was developed; providing sufficient data extracts for readers to assess the interpretation provided; giving rival explanations and suggesting alternative ways of organising the data; and considering power relations within the research;
- Showing complexity within the data including negative cases, multiple explanations offered by respondents and the contextual nature of respondents' accounts.

I provide a summary of how I followed these guidelines in Chapter 9 (section 9.6).

The approach reflects a modified 'realist' position since it acknowledges both that social structures exist (are real) (although may not be directly knowable) and that knowledge is socially constructed as suggested by postmodernism (Brewer, 2000). Willig (2012) argues that there is little difference between such an approach and a 'moderate' social constructionist perspective. As described above the latter is the position I adopted with regard to my object of study, the 'volunteer'.

In sum, taking an ethnographic approach in order to get close to the lived reality of volunteers meant that I had to deal with the issues such an approach raises, namely how to ensure that the 'truth' claims I made were legitimate. In casting 'volunteer' as a social construction I needed a way of acknowledging that there may be alternative explanations. Therefore, I adopted a reflexive approach allowing me to acknowledge my part in the 'production' of the research, including the interpretation of the findings. As Willig (2012) points out 'reflexivity ought to be an integral part of any qualitative study because meaning is always *given* to data and never simply identified or discovered within it' (p. 6, original emphasis).

I have taken time to set out the above as the issue of how I dealt with 'truth' is key in underpinning my thesis. The following sections of this chapter describe the research process using Brewer's guidelines for reflexivity to legitimise the ethnographic account in the following chapters.

3.3 Research context

I undertook participant observation in two hospices, extended conversations with relevant members of staff and an analysis of relevant hospice documents. In this section I discuss how I chose and accessed the fieldwork sites and considered ethical issues.

3.3.1 Choosing fieldwork sites

In order to ensure that what I discovered about volunteering was not an artefact of an individual organisation's 'culture' but was located in the wider sociocultural milieu, I undertook fieldwork in two hospices for adults. The aim was not to draw comparisons between volunteering practices but to provide richer data. There was nothing in the literature to suggest that the nature of volunteering *per se* depended on measurable characteristics of a hospice, such as number of beds, services offered or the cultural or socioeconomic makeup of the local population. However,

in order to focus on the *nature* of the volunteer role, I aimed to follow volunteers in different settings so chose hospices involving volunteers accordingly. Since my research questions were most suited to being answered by data from settings where there was maximum scope for interaction between social actors, I focused on hospice-based volunteers rather than those involved in patients' homes. Bearing in mind K.M. DeWalt and DeWalt's (2011) pragmatic approach to fieldwork choices, I also noted that there are relatively few hospices involving volunteers in this way in the UK (Morris, Wilmot, Hill, Ockenden, & Payne, 2013) and that researching in patients' homes would have also presented additional challenges in gaining ethical approval as well as in the practical conduct of the research.

My PhD supervisors had established research links at my first fieldwork site (to which I gave the pseudonym 'Flora House') so negotiating access was relatively straightforward. I chose the second fieldwork site ('Daisy Hospice') as, from information on its website, it appeared similar to the first site in terms of the number of volunteers involved across a similar range of services. It was also closer to my home which reduced travelling time and fatigue during fieldwork. However, living in the community which the hospice served raised unforeseen ethical difficulties which I discuss in section 3.3.3.

3.3.2 Gaining access – gatekeepers

Access to the field usually involves negotiation with 'gatekeepers' (Brewer, 2000). My supervisors informed the Head of Clinical Services ¹⁰ at Flora House about my research as an initial introduction (the hospice had previously been involved with research and was keen for this to continue), and I arranged to meet her to explain the research in more detail. She contacted managers of the departments in which I was interested in researching, and these managers nominated a volunteer for me to 'follow' and made the initial contact. This process took place over two months. I therefore gained access easily which, as a neophyte ethnographer, was reassuring, but it led to some misunderstandings. For example, one head of department thought I wanted to interview volunteers rather than spend time with them *in situ*. However, once in the field, I was able to renegotiate successfully. Hammersley and Atkinson (2007) warn that 'gatekeepers may exercise some degree of surveillance and control shepherding the fieldworker in one direction or another' (p. 51). In the early stages of fieldwork, I was grateful for the 'leads' I was given but reflecting later, I wondered whether the hospice, wishing to portray

¹⁰ Job titles are also pseudonyms to preserve anonymity.

itself in a good light, identified the 'high value' volunteers such as 'Ken' in the day hospice (Chapter 5 and Chapter 7). As fieldwork continued and I became a familiar figure, I approached volunteers myself to invite them to participate.

Hospices collaborate with each other in shared initiatives and an umbrella support organisation exists which organises regular conferences and events, Hospice UK (<https://www.hospiceuk.org/> accessed 6 August 2018). Hospice staff therefore know staff from other hospices. With this in mind I sought the advice of the Head of Clinical Services at Flora House about the most appropriate member of staff to contact at Daisy Hospice. She offered to make the contact on my behalf and I met with the Head of Clinical Services at Daisy Hospice to explain the project. I then separately met with the Volunteer Manager and the manager of each department in which I wished to research, thus working through 'tiers' of gatekeepers. I had not experienced this at Flora House and was initially frustrated by the extra time it took. However, I came to see it as an important part of fieldwork and an opportunity to find out more about the way the hospice involved volunteers.

I later wondered whether the relative ease with which I accessed volunteers in what I was expecting to be 'protected' environments, was because of their 'low' status within the hospice hierarchy; and as such, they were not seen as worthy of more stringent gatekeeping.

3.3.3 Ethical issues and consent

The overarching principle of research ethics is to ensure that the process does not harm or exploit anyone involved, and to ensure that the privacy of all those concerned is respected (BSA, 2002). Harm can be physical, social or psychological (BSA, 2002), and those involved include the researcher herself and all those with whom she has contact, regardless of whether or not they are directly involved in the research. I describe how I approached these issues in this section.

Ethics in ethnography are not straightforward. Hammersley and Atkinson (2007) provide a typology of the standpoints fieldworkers can take (pp. 219-120):

- *Ethical absolutism* – the strict adherence to an ethical code of practice and the total avoidance of research strategies that are considered 'illegitimate';
- *Ethical situationism* – the evaluation of the costs and benefits of different approaches based on context and the legitimacy of the research aim, but with an overriding aim to avoid harm;

- *Ethical relativism* – the application of different ethical principles according to local and individual values and context;
- *Machiavellianism* – ethical considerations are not a priority.

Like Hammersley and Atkinson (2007) I opted for ‘ethical situationism’ since this offered a realistic approach allowing for the dynamic nature of participant observation (that is, that anything can happen and thus the research context changes from moment to moment), while maintaining the imperative to avoid harm. This last issue was particularly important since my research would involve contact with hospice patients who are ‘vulnerable’ actors (Liamputtong, 2007).

Before starting the research I gained ethical approval from The Open University Human Research Ethics Committee. Since both hospices required volunteers in patient- and family-facing roles to have enhanced clearance from the UK Disclosure and Barring Service to protect clients, I expected them to require this from me as well. However, neither hospice required this since I was not researching specifically with patients and would not be alone with a patient as I was following volunteers. During my fieldwork I was therefore careful to ensure this was the case and achieved this apart from one occasion in a drop-in day hospice session at Flora House when I was on my own with patient for a short time. This resulted in a conversation that I found emotionally difficult. I cannot report the full episode as I did not have ethical approval to collect data from patients but, reflecting on our conversation while writing Chapter 5 brought home to me how this patient located herself relative to the ‘performance’ of ‘living’ (Goffman, 1959/1990). This is an example of how everything that happens in the field is potentially data and exposes the challenges of ethics in participant observation including those of informed consent to which I now turn.

Since participants must agree voluntarily to be involved in a study and this agreement should be based on full and open information (Christians, 2005), I gained informed signed consent from staff and volunteers after providing written information about the study (Appendix D). I approached only those staff who had direct contact with the volunteers I was following and therefore whose interactions I observed, such as the day hospice staff (Chapter 5), the cooks (Chapter 6) and the Bereavement Team Coordinator (Chapter 8). Participants were free to leave the study at any time. If they did so before I had begun analysing the data, I would have destroyed any data pertaining to them if they wished. No participant withdrew. I made it clear to all patients and their visitors that I was a researcher interested in volunteers. I carried information sheets

(Appendix B) to give to anyone who asked for more details, although during my fieldwork only two relatives took one.

I assured everyone involved in the study of anonymity and confidentiality. I use pseudonyms in fieldnote excerpts throughout this thesis. I restrict the description of volunteers below to preserve anonymity. I did not specifically ask people their age, although many told me or gave a strong indication, nor how they identified regarding gender. All told me about their current or most recent paid work but, since this could potentially identify them, I state this only where unavoidable, for example, in the case of the volunteer care assistants in Chapter 7. I discussed my fieldnotes only with my supervisors. I did not disclose any confidential participant or patient information and did not record any information given to me 'off the record'.

As I had privileged access to the 'insider' workings of the hospice, it was possible that I may have witnessed an event which posed an ethical dilemma for me as a researcher potentially compromising the boundary between maintaining objectivity and preventing harm (de Laine, 2000). I agreed with my supervisors that I would discuss any concerns with them before disclosing what I had seen with hospice staff. Although I had no need to do this, the plan was based on the possibility of witnessing sub-standard care. However, reflecting *ethical situationism*, I found that from time to time I had to make a choice about whether to intervene in 'real time'. For instance, at Flora House, I knew from an earlier shift with a volunteer in the inpatient unit that a patient had begun to have trouble holding drinks safely. This information had not been passed onto the next volunteer I followed. My dilemma was whether to say something or not. I chose to remain silent in order to avoid wittingly 'changing the field' but worried nevertheless, although in the end there was no safety issue. An occasion when I may have modified a volunteer's behaviour occurred when volunteer 'Katy' (see Chapter 6) asked me if others I followed on the supper shift also refreshed the patient water jugs. I felt conflicted: I could demur or tell the truth, risking influencing her activities, but maintaining my good relationship with her. I chose the latter, telling her that they had not done so. The next time I followed her she did not change the water jugs and I wondered if I had therefore changed the field. This demonstrates the complexity of the fieldworker's identity work.

During fieldwork I ensured that the research process did not negatively impact on the needs of patients and their families. For example, when following volunteers in the inpatient unit, I chatted to them only when they were not busy with their duties. I also did not follow volunteers in one-

to-one situations – for example, complementary therapy volunteers providing aromatherapy and volunteers giving personal care. This would have required consent from patients which, particularly for sicker patients, would have been difficult to acquire, as well as impractical given the relatively short time some patients used hospice inpatient services. Although volunteer-patient interaction was not a focus of my study, on the occasions when volunteers were working with a staff member, such as those I describe in Chapter 6, it would have been useful to have seen what was going on. In these instances I relied on volunteer reports of what had happened. This was a limitation of my approach.

An unforeseen ethical issue arose when I was referred to Daisy Hospice to access complementary therapy after being diagnosed with a life-threatening illness. Although I had finished fieldwork by this time, I declined the referral to avoid compromising my ongoing relationship with the hospice and to ensure that I maintained my ‘researcher’ identity. This was an unanticipated problem of researching in the community in which I live.

In order to ensure my personal safety during fieldwork, I followed lone working guidance set out by The Open University. At no time during fieldwork did I feel unsafe so did not need to call on this. However, I was aware that I could experience some personal distress researching in a sensitive environment such as a hospice (Rager 2005; Woodby, Williams, Wittich, & Burgio, 2011). Indeed, I found the constant exposure to death and dying emotionally draining. Unlike the volunteers who mostly spend only one shift a week at the hospice, I was there on several days per week and thus was drawn into the patients’ individual stories. Each time I arrived, it was impossible not to notice that a patient was no longer there or that someone’s condition had worsened. In recognition of the negative effect exposure to such an emotionally charged environment can take on researchers’ ability to undertake their work (Seymour et al., 2005), I helped to establish a fieldwork support group at The Open University facilitated by a member of academic staff. This provided monthly sessions for research students undertaking fieldwork with human participants. Providing a form of peer-debriefing and support, was helpful in relieving the intensity of my experiences, and aided my reflections on my experiences.

3.4 Fieldwork sites, settings and volunteers

This section introduces the fieldwork sites and settings in which I researched, and the volunteers I followed. Since the hospice buildings themselves are part of the ethnographic data, detailed descriptions and analysis of the fieldwork sites are in Chapter 4. Differences between the

populations served by the hospice and of volunteer characteristics, such as gender and age, were not noticeable as themes in the analysis of my data and so I do not draw attention to them in the data chapters. I provide them here to give a rounded picture of the fieldwork sites and participants. A summary of the volunteers I followed is in Table 2 at the end of this section.

3.4.1 'Flora House'

Flora House is in a large town in southern England. At the time of my research it served a population of approximately 259,000 (ONS, 2018), including some from surrounding rural communities. Based on the most recent census data (2011), between 53% of the population declared themselves Christian, 4.8% Muslim, 2.8% Hindu and 0.2% Jewish (ONS, 2013). At the time of my fieldwork the hospice was voluntary-managed, receiving approximately 22% of its funds from the NHS. It provided a 15-bed inpatient unit, a hospice-at-home service, day care activities, lymphoedema clinic and patient and family services, including pre- and post-bereavement care. Volunteers were involved in the inpatient unit, day care activities and patient and family services, and therefore I researched in these settings.

Around 600 volunteers supported the hospice, most in fundraising, including retail shops. A volunteer manager and her deputy, both paid staff, were responsible for the recruitment and management of volunteers.

3.4.2 'Daisy Hospice'

Daisy Hospice is also in a large town in southern England. The hospice served a population of approximately 288,000 (Office for National Statistics 2011 Census website, https://www.nomisweb.co.uk/census/2011/postcode_headcounts_and_household_estimates, accessed 16 August 2019) from the wider area in which it is situated, including several smaller towns in three local authority areas. Based on ONS census data for 2011 between 52% and 60% of the population in each local authority area identified as Christian, between 3% and 5% Hindu, between 2% and 10% Muslim, and between 1% and 14% Jewish. At the time of my fieldwork the hospice was voluntary-managed, receiving less than 20% of its funds from the NHS. It provided a 12-bed inpatient unit (IPU), a hospice-at-home service, day care activities, and a bereavement service. Since the latter provided services to anyone who had been bereaved in the local area, regardless of connection with hospice services, I decided not to follow its volunteers as they would fall outside my definition of volunteers in end-of-life care. I therefore followed volunteers in the inpatient unit and day care activities only.

Over 630 volunteers supported the hospice services, with over half in retail shops and a warehouse. Volunteers were supported by a volunteer manager and assistant (both paid staff) responsible for the recruitment and retention of volunteers, and for supporting hospice staff in managing volunteers.

3.4.3 Day hospice sessions and volunteers

Hospice day services in the UK typically provide a range of both therapeutic and social activities (Hyde, Skirton, & Richardson, 2011), and I saw this at both fieldwork sites. At Flora House day hospice activities comprised five-hour sessions forming a twelve-week 'programme' offered on two days a week (patients attending on one day only) and a drop-in session on a third day a week. The 'programme' and drop-in sessions are described in Chapter 5. Three volunteers supported each session (a different 'team' for each). I followed a total of seven 'general' ¹¹ volunteers in the drop-in and 'programme' sessions. By contrast Daisy Hospice offered a wider range of day sessions, although only one ran for a full day and involved more than one volunteer. I followed the four general volunteers supporting this, although a rota operated so that three were 'on duty' in each session.

Apart from one volunteer in her 40s, all were in their 60s to 80s and retired. Apart from two men at Flora House, all volunteers were women. This pattern is typical of UK hospice volunteers (IVR, 2003), although more recent data are not available. At both hospices the sessions were led by a senior nurse, supported by two staff nurses and a healthcare assistant at Flora House, and just a healthcare assistant at Daisy Hospice. At Flora House the hospice chaplain (also a paid member of staff) attended the sessions from time to time. At Daisy Hospice other staff members including a rehabilitation assistant, a physiotherapist and an occupational therapist also attended.

Volunteer complementary therapists also supported the sessions, two at Flora House and three at Daisy Hospice (two at any one time). Because they worked one-to-one with patients I did not specifically set out to follow them, but as the analysis of my fieldnotes developed, I noticed differences between the way their roles and those of the 'general' volunteers were constructed which seemed important (and became the topic of Chapter 7). I therefore specifically aimed to follow the volunteer complementary therapists at Daisy Hospice. A volunteer rehabilitation

¹¹ Throughout this thesis, I use the term 'general' volunteer to refer to those volunteers who undertake tasks which require no specific previous training, such as greeting patients, serving food and drink, clearing up, and chatting to patients. I use the term 'professional' volunteers to refer to those who offer skills requiring specific training, such as complementary therapy or hairdressing.

assistant, art therapist and chaplain also supported the sessions, although did not attend every week. Apart from the complementary therapists at Flora House and rehabilitation assistant at Daisy Hospice, who I estimated to be in their 40s, all the 'professional' volunteers were in their 60s.

At Flora House between five and nine patients attended the 'programme' sessions during the time I observed. The majority had cancer, but other diagnoses included Parkinson's disease, motor neurone disease and chronic obstructive pulmonary disease. Up to five patients attended the drop-in sessions, most accompanied by a spouse or a friend. At Daisy Hospice between six and twelve patients attended each session. One patient had a diagnosis of cancer, and others had diagnoses of Parkinson's disease, multiple systems atrophy or heart failure.

Day hospice volunteers are the subject of Chapter 5, with volunteers offering professional skills considered in Chapter 7. A summary of the numbers of volunteers I followed is in Table 2.

3.4.4 Inpatient unit and volunteers

The hospice inpatient units provided medical and nursing care for patients in the last weeks of life as well as symptom control for others who typically stayed for a few days before returning home or to a nursing home. Both units were run by a large team of clinical staff including doctors, nurses and healthcare assistants, supported by a ward clerk, spiritual care workers, physiotherapists and other allied health professionals.

At Flora House 50 general volunteers supported the IPU in four two-hour shifts Monday to Saturday between 9.30 am and 7 pm, and three shifts on Sundays between 9.30 am and 4 pm, although there were half-hour gaps between the official shift start times. I followed ten volunteers across these shifts. Volunteers worked in pairs, although gaps in the rota meant that some I followed worked alone. Most covered one shift per week (always the same day and time), but some on the supper shift volunteered fortnightly.

At Daisy Hospice around forty general volunteers worked in pairs to cover three three-hour shifts six days a week between 9.30 am and 7 pm: morning (breakfast), afternoon, supper – these were timed to overlap or be contiguous. On Sundays there was no supper shift. I followed twelve volunteers across all these shifts.

I followed one care assistant volunteer at Flora House and two at Daisy Hospice. No other volunteers were in this role at the time I observed except at Flora House where a member of the clinical staff retired and returned as a care assistant volunteer but resigned after only a few shifts. Therefore, I was not able to follow her.

Apart from four 'A' level or university students and three volunteers aged between early 30s and early 50s, all the volunteers were in their 60s or 70s and retired. There were two male volunteers at Flora House and four at Daisy Hospice. Staff with volunteer contact included the kitchen staff at both hospices, healthcare assistants and nurses.

Inpatient unit volunteers are the subject of Chapter 6 and care assistant volunteers are the subject of Chapter 7.

3.4.5 Bereavement team activities and volunteers

As explained I followed bereavement team volunteers at Flora House only. They were part of a hospice-run service offering wider social support to patients and carers. Although volunteers were involved in other aspects of this work, for example, supporting a regular carers' social event, I followed only bereavement team volunteers to make the most of my limited time in the field. Some volunteers worked with children, but this was entirely on a one-to-one basis which I could not observe for ethical reasons. Therefore, I followed the adult bereavement team volunteers. As well as undertaking one-to-one support sessions with clients, these volunteers also facilitated social sessions for bereaved relatives (a weekly coffee morning held at a local department store and a monthly pub evening) and ran a weekly telephone support service.

I observed the coffee morning, for which I adopt the pseudonym 'Coffee Time', and telephone support sessions, 'Telephone Support'. Coffee Time ran for two hours on a weekday morning and Telephone Support ran between 6 pm and 8 pm on a weekday evening, and involved volunteers based in staff offices at the hospice telephoning bereaved relatives. I also observed volunteers at two annual memorial events held at a local church, a group supervision session and two training events, one for new recruits to the children's team and the other refresher training in safeguarding. Although I draw on the data collected at these events, I do not specifically describe them for reasons of space.

At the time I observed there were sixteen volunteers in all, most of whom supported at least two of the regular activities on a rota basis. Typically, three volunteers attended Coffee Time and between three and five volunteers were involved at each Telephone Support session. Most of the

team also supported the memorial events. In the course of my observations I met the entire team. However, two volunteers I met only at the memorial services so have not included them in Table 2. The team was led by a paid staff member, 'Gloria', with whom I also undertook an 'extended conversation'. Two other paid staff also worked one-to-one with clients and supervised the volunteers, 'Lily' and 'Tina'.

Of the fourteen volunteers I followed regularly, two were male. One was in their twenties (and related to a member of staff) and one in their forties; the remainder were retired and aged between 60 and early 80s.

Bereavement team volunteers are the subject of Chapter 8.

Site	Flora House		Daisy Hospice	
Setting	General volunteers	Professional volunteers	General volunteers	Professional volunteers
Day hospice	3 in drop-in sessions 4 in 12-week 'programme'		4 in full day sessions	2 complementary therapists 1 art therapist 1 rehabilitation assistant 1 chaplain
Inpatient unit	2 morning 2 afternoon 1 lunch 5 supper	1 care assistant*	7 breakfast 3 afternoon 2 supper	2 care assistants
Bereavement service	14		N/A	
Reception	1*			

* Eli, the care assistant volunteer, also undertook the volunteer Saturday reception shift

Table 2 Number of volunteers followed by site and setting

3.5 Fieldwork methods

A fieldworker is not simply an 'objective' observer but is a *social actor* in their own right performing their own 'personal, emotional and identity work' (Coffey, 1999, p. 1, original emphasis). Therefore, in this section, as well as describing the methods I used, I also reflect on the decisions I took during the research process, beginning with how I approached participant observation.

3.5.1 Participant observation

Participant observation involves the researcher 'taking part' in the everyday activities, interactions and events of a group of people as a way of learning the explicit and implicit aspects of their life and culture (K.M. DeWalt & DeWalt, 2011, p. 1). Gold suggests a 'scale' of observer roles (1958, drawing on Junker, 1952) as follows:

- 'Complete observer' – the researcher is entirely removed from social interaction with informants, for example, watching video recordings (Green & Thorogood, 2004)
- 'Observer-as-participant' involving 'one-visit interviews'
- 'Participant-as-observer', that is the researcher is present in the field and interacts to some extent with informants
- 'Complete participant' (i.e., in this case, becoming a volunteer myself).

Early in my research journey I discarded the idea of becoming a volunteer myself, that is, a complete participant. In both fieldwork sites volunteers were trained to work in a particular setting. As I had limited time for my fieldwork this approach would have made it difficult to switch settings, as well as raising ethical issues. For example, the hospices would have put resource into training me, only for me to 'retire' when the research was finished. It would also have been harder to maintain my researcher 'identity' in the field, so that participants knew that I was researching and not a member of the field.

Since I wanted to see the volunteer role at first hand, I entered the field adopting the 'participant-as-observer' role, that is, privileging participation but consciously observing and later recording what I saw (K.M. DeWalt & DeWalt, 2011). I interacted with participants while they carried out their tasks, did not undertake the tasks myself although occasionally helped (Delamont, 2004) (see section 3.5.2). I found that I needed a different approach in each setting. In the day hospice sessions it was impossible not to become drawn into conversations with the volunteers, staff and patients. Thus, I became part of the field in a way that was not the case in other settings. At the other end of the scale I did not follow care assistant volunteers when they were undertaking personal care for patients, so found myself largely observing the general ebb and flow of life in the inpatient unit while waiting for them to finish (I asked them afterwards what had happened). In common with other ethnographers (for example, Pope, 2005), my approach also changed as fieldwork progressed moving more towards participation. Therefore, the more fine-grained definition of participant observation suggested by K.M. DeWalt and DeWalt's (2011) modified version of Spradley's (1980) typology more accurately reflects my approach. This distinguishes

five 'grades' of participation from not being in the field at all, through 'passive', 'moderate', 'active' and 'complete' participation. My role varied between passive – observing activity but not taking part – and taking an active role.

I undertook around 400 hours of participant observation over nine months following 55 volunteers in two hospices. I sought to establish a pattern of fieldwork which balanced time in the field with writing fieldnotes and reflection, spending the equivalent of three full days in the field each week. I aimed to undertake a sufficient number of each type of session to understand what were naturally occurring events and what was unusual (K.M. DeWalt & DeWalt, 2011, pp. 90-91). I understood that there was a balance to be struck between being clear to participants that I was researching, which risked participants 'putting on a show', and being able to observe naturally occurring behaviour. To this end I followed different volunteers undertaking the same or similar roles both within each fieldwork site and across the two sites. I found that between six and eight sessions with individual volunteers achieved a balance between capturing the everyday reality of the volunteers and minimising problems of reactivity.

However, serendipity also plays a part in participant observation. Since I was interested in observing how volunteers reacted to the deaths of patients, and it became clear that a patient who regularly attended the drop-in sessions was entering the last few weeks of life, I carried on following these sessions beyond my original eight-session limit. The patient died after the ninth session. However, the following session was given over to a Christmas party. Although I was with the volunteers when they were told the patient had died, they could not talk about it as the room was full with patients by this time. This extension of my schedule meant that I was able to observe only four 'programme' sessions as the day hospice closed over the Christmas period. I also missed volunteers' reactions to a death at Daisy Hospice when a day care patient died just after I had finished observations.

As suggested by K.M. DeWalt and DeWalt (2011), to gain a more rounded understanding of the ethnographic context I attended various other sessions with volunteers. In addition to those listed above in connection with the bereavement team, I observed one volunteer undertaking reception duty (see Chapter 4) and, at Daisy Hospice, an evening support and training meeting for volunteers during part of which I presented my project. I attended a staff meeting in the inpatient unit at Daisy Hospice during which I also presented my project. I treated all such contacts as observation opportunities (K.M. DeWalt & DeWalt, 2011). Unfortunately, no further volunteer

training was planned during my period of fieldwork at either hospice and, apart from the bereavement team, no other team held supervision sessions. The sessions I followed and hours of observation are listed in Table 3.

In addition to attending to what people say and do, ethnographers also use the materiality of the spaces inhabited by their participants, including the built environment and 'the 'thing-ness' of things', to understand their participants' worlds (Hammersley and Atkinson, 2007, p. 134). I therefore considered the hospice buildings, their layout and juxtaposition of spaces, and the arrangement of objects as part of my analysis. The resulting analysis is the focus of Chapter 4.

However, the central task of fieldwork is to understand a '*peopled* field' (emphasis added) and this is achieved through social interaction and shared experience (Coffey, 1999, p. 39). Therefore, my identity in the field and the relationships I developed were central to the research process. I consider these in the next section.

Setting Site	Flora House	Hours	Daisy Hospice	Hours
Day hospice	9 drop-in sessions	50	8 day care sessions	49
	1 Christmas Party	5		
	4 'programme' sessions	22		
Inpatient unit (‘general’ volunteers)	6 morning sessions	Unclear 8	13 morning sessions	58
	4 afternoon sessions		7 afternoon sessions	23
			4 supper sessions	12
	8 lunch sessions (plus one with no volunteer)	18	N/A	
	10 supper sessions	20	4 supper sessions	12
Inpatient unit (care assistant volunteer)	8 sessions	28	16 sessions (8 with each volunteer)	60
Bereavement team	6 ‘Telephone Support’	12	N/A	
	7 ‘Coffee Time’	14		
	2 memorial services	5		
	1 supervision session	2		
	2 training sessions	4		
Reception	1 session	3	N/A	
Other sessions	3 training sessions (2 x child bereavement team new members)	4	1 support/training evening	2
	1 x update on adult safeguarding)	2	1 IPU staff meeting	1
TOTAL HOURS		197		217

Table 3 Participant observation: number of sessions and hours undertaken

3.5.2 Self-presentation, research identity and relationships in the field

Before entering the field, I considered how to present myself, both in terms of my physical appearance and my researcher identity. Clothing is an important consideration for ethnographers

(Jenkins, 2014). I dressed to fit in with those hospice staff and volunteers who did not wear uniform, somewhere between casual and smart-casual, deliberately avoiding appearing like an inspector or official of some kind. Jenkins reports a similar quandary when she chose to wear blue scrubs in hospital-based research. She was 'outed' by a respondent who said 'Oh, I get it. Scrubs are like your camouflage' (2014, p. 530). I was therefore effectively trying to camouflage myself.

At both hospices, staff and volunteers wore badges indicating their name and position. I discussed what I should wear with gatekeepers at both hospices. As a result, at Flora House I wore my university identity badge since the hospice had previously hosted research so staff were used to university researchers. Staff at Daisy Hospice issued me with a photo-ID badge which used 'Volunteers in Hospices Research Project' as my 'job title'. Both solutions made it clear that I was a researcher.

It takes time to develop rapport and trust in the field (Wolcott, 1995). I adopted a role somewhere between colleague and researcher – or somewhere between professional and personal – although I was not really either (Coffey, 1999). Becoming an 'insider' is an important strength of participant observation (K.M. DeWalt and DeWalt, 2011) and the researcher's role typically changes during fieldwork from 'outsider' to 'insider', moving from overt to somewhere closer to covert research (Walshe et al., 2012). As fieldwork progressed I became a familiar figure in the hospices participating in the everyday world of the volunteers. However, I experienced some moral discomfort cultivating relationships for research purposes (de Laine, 2000, p. 19). I made it clear when taking consent that 'anything you say or do may be taken down and used as data' (Hammersley & Atkinson, 2007, p. 210) and, unless participants specifically asked for something to be 'off the record', I treated everything they did and said as data. However, participants could forget that I was a researcher, especially as I tended not to make notes in view of participants. In fact one volunteer asked me why she had not seen me making notes. I explained that I did not want the volunteers to feel I was keeping tabs on them, but I felt awkward responding to her question, as if I was hiding something. Other ethnographers have reported similar uneasy feelings, for example, Lawton (2000). The feeling of discomfort extended into the analysis and writing up phases of the research. As I examined my data critically through lenses of theoretical concepts, I imagined that my participants would have had no idea their data were being used in what could appear to be an unsympathetic and perhaps negative way.

I described above how I adopted different approaches to participant observation depending on the setting in which I was observing (Walshe et al., 2012). While I justified these approaches as

helping to minimise the impact of research on the activities I was observing, on reflection I realised that I was also trying to assuage my feelings of being 'out of my comfort zone' caused by being in an unfamiliar and, at times, emotionally charged, setting. Part of the problem was what to do physically to look natural since I had to physically 'be' somewhere (Coffey, 1999, p. 73). This was particularly difficult when following Eli, a volunteer care assistant at Flora House, since I had to wait for her in the corridor while she undertook personal care in patient rooms (Chapter 7). The corridor was a place of passage and of movement, and I felt out of place and without a role. Similarly, at Daisy Hospice I sometimes felt awkward accompanying volunteers into patients' rooms. I wrote in my field diary, '....don't like trooping in with the volunteers especially in the twin rooms when we file past the bed [and therefore patient] nearest the door to get to the patient near the window'. As I grew into my researcher role, this *embodied* aspect of fieldwork (Coffey, 1999) became easier. One way in which I dealt with these 'performance' issues and which helped me to feel more comfortable was to offer to help. I made tea, cleared up, loaded and unloaded dishwashers, put things away, ironed, and folded laundry. Helping gave me 'social capital' facilitating relationships with participants and enabling useful conversations.

Research in healthcare settings is commonly undertaken by 'insiders' such as nurses or other healthcare professionals (Walshe et al., 2012) – for example, Seymour's (2001) study of death and dying in an intensive care unit. I have never been a healthcare professional and, at the time of fieldwork, my experience of healthcare settings was limited to the volunteering I had undertaken in wards for people with dementia and chronic mental health conditions (see Chapter 1), and to visiting others in hospital. Therefore, in the anthropological sense, I was an 'outsider' and came to the field without any privileged understanding of it. Although this meant that I could have misinterpreted an event, I consider my lack of preconceptions to be a strength of this study. In terms of my own identity construction, not being a healthcare professional may have helped me form better relationships with the volunteers than otherwise would have been the case since I was more 'like them'. They may have been less welcoming if I had been a healthcare professional. Similarly, I had no 'status' with the clinical staff, which also meant that they may have also been more forthcoming since they had no reason to feel threatened or judged by me.

3.5.3 Writing fieldnotes

I wrote fieldnotes describing what I had observed as soon as possible after the end of each session. I aimed to write an account in chronological order and in as much detail as possible. I focused on events: what happened, who was present and what they were doing, and the

communication that occurred (Green & Thorogood, 2004). I kept my impressions and embryonic analyses separate, thus carefully distinguishing descriptive from analytical fieldnotes (Emerson, Fretz, & Shaw, 2011). I kept a separate fieldwork diary to record personal feelings.

During sessions I carried a small notebook and pencil to make notes, doing so either unobtrusively or briefly leaving the session. However, I found these notes interrupted my memory flow and I was better able to reconstruct a session if I used them only to add details such as exact quotations. I often remembered additional material while preoccupied with everyday activities such as watching television or cooking. In these cases, I scribbled a note on a convenient piece of paper and updated my fieldnotes later.

Despite taking care to be as 'objective' as possible in making fieldnotes, I was aware that they are not 'raw data' (de Laine, 2000, p. 148) since they have been produced through social processes in the field, and by what I attended to and considered important to record, both consciously and unconsciously. They are therefore a construction in themselves (de Laine, 2000) based on my own construction of the object of study. In addition, as a lone researcher there was no corroboration of the 'evidence' from another fieldworker. A fellow PhD student, in a discussion about our respective projects, said to me in surprise, 'Your fieldnotes are your data?' as if I was inventing my own data, going to the heart of the issue of legitimacy discussed above. Not only is memory fallible, but the ethnographer has no control over events in the field. While I was attending to an 'event' something else 'interesting' may have been occurring elsewhere. The beginning of day hospice sessions when the patients arrived *en masse* were a particular challenge. As I wrote in my field diary bemoaning the process, '....all the meaty stuff happens at once...'. However, by observing over a period of time and in two fieldwork sites, I hoped to counteract this.

During the period of my fieldwork I also made initial analyses along the lines suggested by Emerson et al. (2011, pp. 123ff) for developing 'in process memos'. Here I developed analytical ideas which I could use as a focus for subsequent fieldwork. However, I tried hard to maintain a balance between focusing on specific issues and approaching each session in as 'fresh' a way as possible.

3.5.4 Leaving the field

Fieldwork has to end at some point (Delamont, 2004) and I gave myself a year in which to complete the whole fieldwork process including gaining access. When setting up fieldwork at each site I established with the main gatekeepers my overall end date. As I moved from one setting or

shift to another I set interim 'leaving' dates with department heads and volunteers. I arranged to revisit each hospice to report on my findings although, at the time of writing, this has yet to occur.

I found finishing fieldwork at each site raised emotions similar to those of leaving a job that I had enjoyed, but from which I was ready to move on. I experienced a combination of sadness at leaving behind the people with whom I had shared a relationship and excitement to be moving to a new phase. I was also physically and emotionally drained, so leaving was something of a relief.

3.5.5 Extended conversations

I chose not to undertake 'formal' interviews or focus groups with participants, although these are commonly used alongside participant observation and other data-gathering methods (Brewer, 2000). Research methods should be chosen based on their 'fit' to the research question. While interviews produce data which help researchers understand participants' views, experience and interpretations (Green and Thorogood, 2014), and reveal discursive strategies (Hammersley, 2005), I was primarily concerned with understanding what volunteers do and the structures and processes underpinning this for which observation techniques are more appropriate. In interviews participants say what they do, but observation allows the researcher to see what they do (Walshe et al., 2012). My decision was also based on my concern that interviews would dominate the analysis of my data. Comparing my experience of research based on semi-structured interviews (Burbeck & Willig, 2014) with the present project, interview data appear to have greater legitimacy than fieldnotes since they provide a verbatim record of what people said whereas fieldnotes are simply what a fieldworker chose to record of what happened. However, it can be argued that interviews themselves are a 'false' situation. They produce data through a contrived interaction between participant and researcher, and are also reliant on memory which itself is a construction and 'cultural phenomenon' (Atkinson & Coffey, 2001, p. 809; Hammersley, 2005). I argue that the two methods are different and focus on different phenomena. While interviews produce data about the experiential realities and inner life-world of participants, revealing their discursive strategies and resources (Hammersley, 2005; Willig, 2012), fieldnotes can reveal the structural underpinnings of the object in question.

They also require different analytic approaches. Interview data are very 'dense'. Not only can almost every word be treated as a datum, but also data emerge from the (near) juxtaposition of words (such as in oxymorons) and in the relationships between words and meanings. Fieldnotes cannot be treated so 'literally'. Here, data emerge, not from the recorded words, but from the

‘actions’ and ‘happenings’ the words represent and the application of theoretical lenses to understand the meanings these actions symbolise. They are therefore a different kind of data, shedding light on different kinds of phenomena.

However, I needed some information about how volunteering in each hospice was organised and so undertook informal interviews, which I called ‘extended conversations’, with relevant members of staff. I also undertook two such conversations with volunteers I could not otherwise follow, a member of the child bereavement team (whose entire work comprised one-to-one activities) and a trustee (not a patient- or family-facing role). I planned a list of topics to cover during each conversation during which I took notes. Table 4 lists the people with whom I held extended conversations.

Flora House	Daisy Hospice
Head of Clinical Services	Head of Clinical Services
Volunteer Manager	Volunteer Manager
Volunteer Coordinator	Nurse Manager
Trustee	Day Hospice Manager
Volunteer in child bereavement team	
Bereavement Team Coordinator	
Day Hospice Manager	

Table 4 People with whom I held extended conversations ¹²

3.5.6 Document analysis

Documents are ‘produced in social settings and are always to be regarded as collective (social) products’ (Prior, 2003, p.26). I requested hospice documents relating to volunteers from the volunteer manager at each fieldwork site. These included volunteer job descriptions, policy documents, information given to volunteers and documents used by hospice managers. I used these to help me understand how the hospice as an institution constructed the volunteer role. I

¹² Staff job titles changed to preserve anonymity.

also asked for copies of leaflets given to patients, and used these to understand how the hospice constructed and presented its services. A list of documents accessed is in Appendix E.

3.6 Data analysis

Data analysis does not just begin once data are collected but starts in the formulation of research questions, proceeds throughout data collection and continues throughout writing up (Emerson et al., 2011). From my reading of the existing literature I began fieldwork with some ‘foreshadowed problems’ (Delamont, 2004). These included the possibility that staff could feel threatened by volunteers because of a perception that the volunteers were taking their jobs, and that there was a tension between the hospice movement’s belief that volunteers bring a different kind of care compared with staff, while at the same time saving the hospice money.

Following Brewer (2000) I approached the overwhelming volume of fieldnotes by splitting ‘analysis’ (bringing order to the data) from ‘interpretation’ (attaching meaning and significance to the data) but was constantly aware of an overlap between the two. Conscious that the process must be systematic and thorough (Brewer, 2000; K.M. DeWalt & DeWalt, 2011), I undertook initial ‘indexing’ of my fieldnotes using Nvivo software (QSR, 2017). I organised the index codes into hierarchies forming analytical topics or themes. Over many iterations I refined the index codes and resulting hierarchy, both by working through the material attached to each code and by revisiting the original material in light of new insights. In this way the material was indexed as follows (material could be included in more than one code):

- Descriptive material (hospice spaces, hospice procedures and ‘occasions’ such as birthdays)
- Descriptive material based on interactions (such as handover, tasks being undertaken and specific incidents)
- Anomalies
- Participant views (divided by topic and actor type)
- Volunteer ‘characteristics’ (both specific characteristics such as conscientiousness, and roles volunteers took on, such as advocate and quasi-professional)
- Death-related codes
- Food-related codes
- Interpretative codes (codes which interpret the data – see below)

- Research methods (such as volunteer or staff reaction to me, my reactions in the field, codes used to analyse my fieldwork diary)
- Document analysis codes (codes used to analyse documents).

In meetings with my supervisors during and after the period of my fieldwork I discussed possible emerging themes which I refined over successive iterations to arrive at the following: boundaries; the production of a 'good death' through a performance of 'living'; food-related practices in relation to living and dying; hierarchies; and staff-volunteer relationships.

Having produced this framework of topics and themes, I found that Nvivo did not allow me to 'layer' codes in a sufficiently flexible way to record my interpretation of the data. I worked with pen and paper from this point. I examined relationships between codes and the patterns generated. A breakthrough came when I compared how I had used a code across the different settings (day hospice, inpatient unit and bereavement team). These comparisons made it clear that there were major differences in the volunteer role in each setting. Although similar 'elements' were there, the roles were different. These elements included volunteer access to patient information, the volunteer role as 'host', the relationship between staff and volunteers and the extent to which roles were 'bounded'. I also considered 'negative' cases (Brewer, 2000), that is, data which are 'counter' to other data. This led me to realise the important differences between the 'general' and 'professional' volunteers and between professional volunteers in the two settings in which they were involved (day hospice and inpatient unit).

As K.M. DeWalt and DeWalt (2011) suggest, this stage of analysis can feel like a 'mystical' process with some connections and insights made sub-consciously (p. 179). I also returned to my fieldnotes and documentary sources from time to time in order to check out theoretical ideas. I abandoned some topics, largely for reasons of space in the thesis or because they were concerned more with the hospice and its practices than with the volunteers. These included issues around hygiene and contamination in the inpatient unit.

Hammersley and Atkinson (2007) advise that the writing process in ethnographic work is a key part of the analysis, and I found that successive attempts at 'writing the data' produced new analytic insights. For example, I did not realise the importance to my analysis of the contrast between the 'professional' and general volunteers until I began to write Chapter 5. The result of this was to consider the professional volunteers separately from other volunteers which gave me

the key to understanding the professionalised nature of death and dying (Chapter 7). The importance of how the finished text is generated cannot be overstated in ethnographic work.

3.7 Summary

In this chapter I have described the research process. I have shown how I arrived at my methodological position through an understanding of the constructed nature of my research object, the 'volunteer'. I then showed how I dealt with the ontological issues around the nature of reality in ethnography, and how I intended to address these through appropriate reflexivity. I described how I addressed the ethical challenges of participant observation, which require the researcher to achieve a balance between avoiding influencing the behaviour they are observing while respecting the privacy and consent of participants but ensuring that the research aims are met (Walshe et al., 2012). I have also given an account of the data collection and analysis processes and the issues I encountered, and have introduced the fieldwork sites, settings and volunteers.

In the following five chapters, I present my data, starting with the materiality of the hospice buildings and the spaces inside, and how these establish the importance of the life-death boundary.

Chapter 4. Hospice space: the sequestration of death

From its inception the hospice movement aspired to express its ideals architecturally, making it clear from the design of its buildings how it was different from the institutions it was aiming to replace (Worpole, 2010). During my fieldwork I became aware that hospice spaces were used differently by the various actor groups. The volunteers I followed had no access to some spaces and only limited access to other spaces. Therefore, I became interested in how space was used and regulated and how the organisation of institutional space contributed to the construction of the volunteer role. Spaces and the material objects they contain reflect social structures (Giesecking, Mangold, Katz, Low, & Saegert, 2014; O'Toole & Were, 2008), reproducing relationships of power and ideologies (Hallman & Burdick, 2015). An example of this is Foucault's (1975/1977) use of Bentham's Panopticon to demonstrate how an arrangement of space can be part of the production of power (O'Toole & Were, 2008).

The focus of this chapter is therefore on the physical spaces of my fieldwork sites: the hospice from the outside, the reception areas, day hospice spaces and the inpatient units. I explore these spaces to offer symbolic interpretations on how the way they were used demonstrated how the hospices sequestered death and 'protected' the life-death boundary, and how this contributed to the construction of the volunteer role. I draw on medical sociological theory to frame these interpretations, recognising that this is one of many possible lenses through which to view what was taking place. I uncover the clear practical realities of end-of-life care in settings devoted to enabling people to live until they die to suggest what else might be happening in symbolic terms around this life-death boundary. More specifically I contextualise the volunteer role by drawing on Goffman's (1959/1990) theory of regions (outlined in Chapter 2) and Lefebvre's (1974/1991) work on the social production of space (described below) to show how the hospice buildings in which I undertook my fieldwork protected the boundary between life and death, in effect sequestering death while promoting hospice ideology. In addition, I use Douglas' ideas about the polluting nature of death to help understand the importance of the life-death boundary which, as I argue in this thesis, is key to the volunteer role.

4.1 Lefebvre and the social production of space

For Lefebvre (1974/1991) physical spaces have meaning which is *socially produced*. He suggests a four-way categorisation of space based on the relationships between boundaries: accessible space; boundaries and forbidden territories; places of abode; and junction points (Lefebvre, 1974/1991, p. 193). These relationships may change depending on the social relationships of the actors involved and can also overlap (Lefebvre, 1974/1991; Allen & Pryke, 1994). Beginning with accessible spaces, Lefebvre (1974/1991) describes these as ‘... space for normal use.... such use is governed by established rules and practical procedures’ (p. 193). In other words, these are spaces which may appear ‘neutral’ but are in fact rule-governed (Rosenhan, 2016). I would argue that the hospice reception areas, described below (section 4.3), provided examples of these.

Boundaries and forbidden territories are ‘spaces to which access is prohibited either relatively (neighbours and friends) or absolutely (neighbours and enemies)’ (Lefebvre, 1974/1991, p. 193) and may be places of friction since their use can change. In Lefebvre’s example, a house is forbidden space to neighbours and friends until they are invited in but is always forbidden space to enemies. In Goffmanesque terms, forbidden territories usually comprise ‘back’ spaces where preparations for performances in the front regions take place. I argue that the hospice treatment rooms where medication was stored and prepared produced this kind of place. Further, in the hospice, the cold rooms where bodies were placed after death, were prohibited spaces except when relatives viewed a deceased family member. Another example could be the usually accessible corridor space which became ‘forbidden’ when a body was being moved, described below (section 4.5.6) (Lefebvre, 1974/1991).

‘Places of abode’ can be either permanent or temporary (Lefebvre, 1974/1991). I draw on this notion to argue below that the patient rooms become temporary living places. Other spaces such as offices are also a type of place of abode, being ‘exclusive backstage areas’ (Howarth, 1996, p. 46).

Junction points are ‘places of passage and encounter; often, too, access to them is forbidden except on certain occasions of ritual import’ (Lefebvre, 1974/1991, p. 193). They exist on the boundaries of prohibited spaces. Howarth (1996, p. 45) describes such places as ‘sites of potential conflict’ between the different actor groups. This could be seen in the patient rooms in the inpatient units which I describe in Chapter 6. However, as Howarth points out, drawing on

Goffman's notion of performance, there is also potential for collusion between actor groups. These are some of the ideas which informed what I explore below.

I begin my exploration of the hospice buildings by considering them from the outside.

4.2 Outside spaces: sequestering death and dying

I drew attention in Chapter 2 to the paradox of the hospice approach which separates dying people from society while focusing on 'living' (Hockey, 1990). This section draws on my data to explore how the buildings and setting of both fieldwork sites emphasised the physical separation of dying people from the surrounding community, reinforcing the heterotopic nature of the hospices. Goffman (1959/1990) defined regions as physically bounded, that is having 'fixed barriers to perception' (p. 231). Therefore, in addition to 'back' and 'front' regions, which I discussed in Chapter 2, Goffman suggests that there is an 'outside' region beyond the physical boundaries of the building. Thus, in addition to performers and their audience, there is a third group of people, 'those individuals who are on the outside of the establishment outsiders' (Goffman, 1959/1990, p. 135). Based on these ideas, I now consider the hospice buildings and their surroundings in terms of a 'performance' given to outsiders.

Although both hospice buildings had been substantially extended, at the core of each site was a building designed for another use: at Flora House a farmhouse and at Daisy Hospice a hospital. These buildings formed the 'public' faces of the hospices. In keeping with the anti-institutional ideology of a counter movement, neither appeared purely functional. Both original buildings were Grade II listed, of attractive red brick with large 'Georgian' style sash windows and were well cared for. Although a former hospital, Daisy Hospice was a low-level building with two storeys plus a limited third storey within the roof space.

Both hospices were situated on the edge of modern 'executive-style' housing estates, in keeping with Dame Cicely's ideal of siting hospices within a suburban setting, providing 'community buildings' since the hospice would serve the local community (Worpole, 2010). Both hospices had clear signs at their boundaries with public space stating their name. This had the effect of alerting 'outsiders' that this space was for a particular audience, thus, I argue, 'controlling' access to the 'front' regions (Goffman, 1959/1990). Neither hospice had substantial physical barriers preventing outsiders from entering or 'insiders' from leaving. Worpole (2010) suggests that

contemporary hospices 'make every attempt to 'normalise' a setting which would otherwise be fearful' (p. 43) and, I suggest, this lack of obvious security aided this endeavour.

As I discussed in Chapter 2, a key plank in hospice ideology is to reclaim the 'natural good death' from modern medicalised and technologised death (Hart et al, 1998, p. 74; Palgi & Abramovitch, 1984). At Flora House 'natural' was invoked through its semi-rural setting, surrounded by grass, trees and shrubs. The hospice buildings also overlooked a large lake accessible to the public. I noticed people jogging or walking dogs along a path round the edge of the lake. A low picket-style fence marked the hospice boundary. Since most of the patient rooms overlooked the lake, patients could therefore watch 'living' taking place a short distance away but living people could not see them.

In order to explore the view of the hospice from the 'outsider' perspective, I walked round the lake. From the opposite side all that could be seen of the hospice was part of the original farmhouse with a church tower behind it. I was struck by the contrast between this pastoral view and the 'drama' of death taking place within the hospice walls. I mentioned my walk to the day hospice staff one of whom told me that the local council had granted planning permission for an extension to the hospice on condition that the view from the side of the lake furthest from the hospice remain unchanged. That is, that the new buildings should not be seen, thus effectively sequestering dying. This appears to be typical of UK hospice buildings as Worpole (2010) states:

In order to fit into their suburban or greenfield settings, hospice buildings are often required not to draw too much attention to themselves, both for planning reasons and for reasons of preferred style (p. 43).

By contrast Daisy Hospice faced a busy dual carriageway, although the building was separated from this by parking spaces, a flower border, a wide pavement/cycleway and metal railings. However, I argue that dying was also effectively sequestered from the community as the inpatient unit was in a new building behind the original hospital and the patient rooms overlooked a courtyard garden beyond, thus invoking nature as far as possible given the urban setting. The original building was mostly used as 'back' space housing offices, the hospice kitchen, a meeting room, staff room and storerooms.

Vehicular access to both hospices was via a 'no-through' road, and I found them both hard to find despite local signs. Others I spoke to during my fieldwork reported similar experiences. Daisy

Hospice was accessible from the main road only on foot, otherwise it was reached via a circuitous route through the adjacent housing estate, a journey of over a mile from the front of the hospice. Difficult access further emphasised the sequestered nature of the spaces.

In this section I drew on Goffman's (1959/1990) notion of 'outsiders' to explore how the setting of the hospice buildings begins to suggest their role as heterotopic and sequestering places, as well as expressing aspects of hospice ideology. I turn now to consider the inside spaces in which volunteers perform their roles: the reception areas, the day hospice rooms and the inpatient units. Plans of the hospices are in Appendix F, Appendix G and Appendix H.

4.3 Reception areas: 'protecting' the life-death boundary

Both hospices had an 'accessible' reception area, kept unlocked while a receptionist was on duty. At other times visitors rang a bell which sounded in the nurses' office/station (at Daisy Hospice the bell was at the side entrance used by both day and inpatients). However, although the reception areas were physically accessible, I argue that they were what Lefebvre (1974/1991) would call rule-governed spaces, in that they were protecting the boundary between living and dying. This section will show how, based on my data findings, this 'protecting' role was achieved and also introduces how the volunteer role was constructed by the hospice.

The reception area at Flora House was accessed through a double set of automatic sliding glass doors. It was light and bright, with windows at the back of the space overlooking a sitting area with a further window overlooking the lake. My initial impression was of an unimposing space. After my first visit I described the entrance in my fieldnotes as follows:

There is no sign above the door on the outside with the hospice name. The area is carpeted. There is no security as such. The area is quite small and doesn't seem designed for people to spend a great deal of time in.

This fits with Worpole's analysis of hospice buildings in which he describes entrances as being 'modest but welcoming' and like a hotel (2010, p. 46). At Flora House, I witnessed a newly arrived patient's relative trying to order newspapers from the receptionist, who told him that this service was not provided. I speculated that he had been convinced by the hospice performance of hospitality and that he may have thought the hospice was like a private hospital or even a hotel where such services are available.

At Daisy Hospice the reception area was in a more functional space compared with that at Flora House (see Appendix H). Many of the building's period features had been retained, including the black and white chequer-pattern tiled floor, pillars and a grand but false double staircase. It was therefore difficult for Daisy Hospice not to invoke the more formal atmosphere intended for the building's original use.

Again drawing on Lefebvre (1974/1991), the 'practical procedures' (p. 193) carried out in the reception areas involved 'signing in' and, for visitors, the giving of badges, which I interpret here as part of the reception 'protecting' function. At both hospices the receptionists sat behind desks facing the outside doors, enabling them to monitor people entering the hospice to ensure they had a legitimate reason to be there. Other than patients, everyone was required to sign in before entering further into the hospice spaces. This prevented 'outsiders' from accessing the spaces beyond where, potentially, dying was taking place, and therefore could be interpreted as protecting the life-death boundary as well as promoting patient safety and privacy.

Visitors to both hospices signed in and out on a sheet of paper on the 'counter' area of the reception desk, while staff and volunteers at Flora House used separate A4 hardback notebooks. Those at Daisy Hospice signed in separate divisions of a loose-leaf file. Thus visitors, staff and volunteers were separated into their institutional roles as they entered the hospice. The notebooks and file were kept beyond the reception desk so that people walked past the receptionist to reach them, relying on the receptionist to recognise them to 'allow' entry. Everyone signed in by recording their arrival time and signed out by recording their departure time. This was clearly a requirement of the fire regulations. Visitors who were not visiting a patient were offered a seat in the reception area once the signing-in process was complete.

The hospice receptionists greeted patients' visitors warmly, often initiating a conversation about the weather or the traffic (I noticed this especially at Flora House). However, when 'professionals' arrived, such as undertakers collecting a body or ambulance staff bringing a patient, I noted that the performance of welcome was not given and the interaction was more muted and business-like. The rituals of arrival undertaken in reception, including the act of welcoming, are part of the performance of hospitality which, as I describe in more detail in Chapter 5, involves actors taking the roles of 'host' and 'guest' (King, 1995) (section 5.1). Based on interpreting my data through the lens of hospitality, I argue that it was in reception that patients and their visitors first took on their role of 'guest'.

At Flora House, patients admitted to the inpatient unit entered via the 'main' reception. On the few occasions I witnessed this, all were either in a wheelchair or on an ambulance trolley, so their 'patient' status was made visible by the technological paraphernalia. As noted above patients did not sign in, although their 'paperwork' in the form of patient notes (at Daisy Hospice these were held electronically) acted as a record of their presence. Also as noted above, at Daisy Hospice inpatients used the side entrance in the extended part of the hospice. The issue of the entrances and exits used by patients is revisited below to show how the routes used partly reveal hospice practice around the sequestration of death (section 4.5.6).

All actor groups in the hospices I studied, apart from patients, wore badges. Goffman (1959/1990) states that 'insignia of office or rank' (p. 34) are part of someone's personal 'front' and are, therefore, part of the performance they give. However, I argue that my data showed it was the institution that created people's 'fronts' by issuing identity labels in order to mark their institutional roles. Visitors were given a sticky label stating 'visitor' designed for single use. Drawing on Underwood (2016) who showed how hospital visitors become liminal within the hospital social hierarchy, I argue that these badges indicated the temporary-ness of visitors and their 'in-between' status. By contrast, staff and volunteers wore 'permanent' badges. Staff badges had their full name and job title, while volunteers' had just their first name and 'volunteer'. At Daisy Hospice badges also included a photograph. The important point for my analysis is that these variances cast volunteers as different to paid staff. I interpreted the inclusion of a surname on the staff badges as creating a more formal and higher status image than the use of just a first name on the volunteer badges which, although may make the wearer appear more approachable, also may make them appear of lesser importance. I revisit the issue of names in Chapters 5 and 6 (section 5.4.2 and 6.4.1).

As well as being spaces where those entering the hospice took on their institutional roles and where 'outsiders' were kept away (although I did not see a specific occurrence of this), I also argue that the reception areas functioned as a buffer between living and dying. For example, at Flora House I attended a training session given by Lily, a member of staff who worked with families providing bereavement care. The session took place in a meeting room accessed directly from the reception area. From my fieldnotes:

Twice, talking could be heard coming from Reception and Tina [senior member of staff] got up (she was sitting near the door) to remove the object which was holding the meeting room door

ajar for ventilation (the room was hot as there were so many people). On the second occasion, Tina said, 'They don't want to hear us talking about death'.

Thus, the reception areas could be interpreted as important spaces for 'living' which were in danger of contamination by talk of death. 'Living' was also exemplified in the easy banter I witnessed between the receptionists, other staff and volunteers. I argue further that the reception spaces were also used to 'protect' living people from encountering deceased ones. On one occasion I arrived at Daisy Hospice to follow a volunteer in the inpatient unit. The receptionist asked whether I was going to the inpatient unit because, *'They're moving a patient – we are holding visitors'*. I knew from experience at Flora House that this meant that a patient had died and was being moved to the hospice cold room. Two women had just signed in ahead of me to visit a patient in the inpatient unit. They did not query why 'moving a patient' meant they could not access their relative. As I did not have ethical approval to collect data from relatives, I did not ask them what they understood by this and, in any case, it might have been insensitive of me to do so. While it is entirely reasonable to assume that they recognised what 'moving a patient' meant in this context and that sensitivities were being observed, in Goffmanesque terms the incident could also be interpreted as a collusion to keep the harsh reality of death from leaking out and threatening the performance of living. A further explanation is that, in entering the liminal role of visitor, they had become passive and subject to easy control (Underwood, 2016). The incident also supports Komaromy's findings in hospitals and care homes that 'the living are stopped in order to move the dead' (2005, p. 188).

I turn now to the issue of reception work being mostly undertaken by paid staff. This was the case at both hospices and contradicts the most recently available data which indicate that volunteers are commonly involved in this function in many hospices (Burbeck, Low, et al., 2014¹³). At Flora House volunteers routinely covered only the weekend afternoon shifts. These were described as *'quiet'* by the volunteer manager, and the volunteer I followed on a reception shift recommended that I bring a book to pass the time. I asked the volunteer manager about the involvement of volunteers only on these shifts. She told me, *'Why pay someone to do nothing? ... Why turn volunteers away when [we have] got someone [who is happy to provide cover]... No one's out of a job'*. Exceptionally, one weekday shift was covered by a volunteer but, as the volunteer manager

¹³ Although the survey did not ask to what extent volunteers were *sole* receptionists.

told me, '*She's been doing it for years and years*'. The manager went on to describe the shift derogatively as a '*social outing*' for the volunteer concerned. These comments suggested to me that volunteers were not viewed as 'professional' but may have been seen as fit only to 'do nothing' and not valued as highly as paid staff. Furthermore, in Douglas' terms, they could be seen as 'dangerous' as they had the potential to replace paid staff. The issue of professionalism and volunteers recurred during my fieldwork and I discuss it further in Chapter 9. At Daisy Hospice a volunteer typically sat alongside the paid receptionist in a support role. I interpreted the apparently subordinate role of volunteers in reception duties and the emphasis on employing paid staff for this role as suggesting the importance to the hospice of the reception area as a boundary between 'outside' and inside, in some ways being located between living and the 'sacred' space of the hospice as a place for dying.

In this section I have shown how the reception areas were 'accessible' spaces but as suggested by Lefebvre, they were also rule-governed forming the boundary between the outside world of the living and the inside space where dying takes place. Here, access to the hospice is controlled, outsiders are kept out and only those with 'permission' to enter did so, fulfilling one of the principles of heterotopia I discussed in Chapter 2. Clearly, controlling access can be considered a key part of adherence to statutory requirements, such as safeguarding patients, as well as a practical security issue, and highlights the institutional nature of the hospice. My analysis suggests the potential for volunteers to be seen as unfit gatekeepers to a space which represents the boundary between life and death. I build on these speculations in subsequent chapters and turn now to consider the day hospice spaces, which also emphasise the separation of life and death.

4.4 Day hospice spaces as 'living' spaces

In Chapter 2 I introduced Goffman's ideas about performance and in this section I use these to examine the day hospice areas to demonstrate some of the ways in which the hospices performed 'living' through the arrangement of these spaces and how they expressed hospice ideology of hospice as 'home'. I consider three aspects of the spaces: how they were named; their physical placement within the hospice; and how the spaces were presented in terms of décor and furnishings.

4.4.1 Naming the space – promoting health and hope

Neither Flora House nor Daisy Hospice used the term 'day hospice' to refer to their non-inpatient services (although I use it throughout the thesis for clarity). Instead the hospices 'packaged' day

services as distinctly separate from inpatient and hospice-at-home provision, adopting names which did not include the hospice name nor the word 'hospice': Flora House used one suggesting healthy living and Daisy Hospice one invoking hope. I have not given the names to preserve anonymity.

Based on a convenience sample of 27 websites of hospices in the UK and Northern Ireland which I undertook in 2017, separating day services from inpatient services under their own moniker seems to be common practice. The majority used functional names: 'Day Hospice' (n = 6), 'Day Therapy' (n = 6), 'Day Services' (n = 5), 'Day Centre' (n = 1), 'Outpatient Services' (n = 1) and 'Supportive Care and Outpatient Services' (N = 1). A few used names focused on wellbeing and health, such as 'Independence and Well-Being Service', 'Keeping Well', 'Living Well Services' and 'Wellbeing Services' (one hospice each term). Two used the name of a founding figure or former patient. One used a name suggesting hope and renewal: 'The Spring Centre'. Since hospices commonly use symbols implying life and hope in their logos (Froggatt & Walter, 1995), the use of such names is not surprising. It should be noted, of course, that the 'audience' for a service is not just its users but, in a marketised healthcare system, also commissioners and funders (Lawton, 2000).

When I began fieldwork at Flora House the term 'day hospice' was included on a sign in the day room, but I noticed that it was not replaced following the redecoration which took place later in my period of observation. The disassociation of day hospice services from other hospice services was mirrored in the physical positioning of the day hospice spaces and their relationship to the rest of the hospice spaces, which I now describe.

4.4.2 Physical placement – separating living from dying

At Flora House the day hospice spaces were on a different floor to the inpatient unit, metaphorically and physically separating living from dying (see Appendix F and Appendix G). Since the hospice was built into a hill, the day hospice on the lower ground floor below the inpatient unit was accessible both from the outside through an entrance at the back of the building and also via stairs and a lift from the inpatient unit on the ground floor. The stairs were accessed via a door which, from the inpatient unit side, required an electronic fob to open. However, a fob was not needed to open the door from the day hospice side. As well as providing a security measure preventing unsanctioned access to the lower ground floor and also reducing the risk of someone with poor mobility using the stairs unaided, the arrangement prevented 'unauthorised' access to

‘living’ by those deemed to be ‘dying’ while symbolically ‘allowing’ the ‘living’ to move to ‘dying’. Komaromy (2005) noted how, once the care home residents she observed were categorised as ‘dying’, it was difficult for them to return to ‘living’ partly in order to conceal death from residents who were ‘living’ (p. 156). However, the lift between the ground and lower ground floors was not secured in any way, a fact pointed out to me on several occasions by day hospice volunteers who were not given a fob when they collected the food for lunch (see Chapter 5). Staff were given a fob but those volunteers who required access to both the hospice laundry and the inpatient unit were lent one (between them) by the receptionist which they returned when they left the hospice. This issue of access to locked spaces – forbidden spaces in Lefebvrian terms – is important in establishing the volunteer place in the hospice social hierarchy and I revisit it in Chapter 7 (section 7.3.1).

As well as the main day hospice room (described below), other day hospice spaces including a complementary therapy treatment room, an office used by the lymphoedema service (part of day hospice packaged services, but not part of this project as volunteers were not involved), toilets and a store room used for craft materials were also located on the lower ground floor at Flora House. ‘Back’ function spaces were also situated on this floor including the laundry, a stock room, housekeepers’ office and an office used by caretaker/maintenance staff. The ‘back’ spaces were ‘protected’ by fob-controlled doors. The outside door into this floor was kept locked so patients rang a bell which sounded in the staff office within the day hospice space. A volunteer or member of staff went to open it, ensuring that access to the day hospice space was protected, with the ‘team’ literally controlling access (Goffman, 1959/1990). By using this entrance, I argue that patients could avoid walking through the inpatient unit, protecting them from the sights and sounds of dying. From my fieldnotes of one of the ‘programme’ sessions:

I overheard one of the nurses saying to the new patient that he could go out through the [name of service] door, ‘....if you don’t want to walk through the hospice’.

By contrast with the space at Flora House, the day hospice room at Daisy Hospice was harder to keep separate from other hospice functions because of its position between the original hospital building and the inpatient unit behind (see Appendix H). The room had an entrance in each of three corners: one from the original building, one into the inpatient unit and one to the side entrance from the carpark. In addition, it had a door to the central courtyard (comprising flower beds and sitting areas), doors to an office and to a small room used for one-to-one sessions between staff and patients, and an opening into the small kitchen shared with the inpatient unit

(accessed from both sides). During the day sessions the door to the inpatient unit and the sign above it were concealed with mobile screens. Electrically operated shutters were available to close off the kitchen and inpatient unit beyond. Physically hiding the inpatient unit from view could be interpreted in dramaturgical terms as preventing patients from seeing performances which were not (yet) intended for them (Goffman, 1959/1990).

However, in terms of preventing interruptions and noise intrusion, neither strategy was entirely successful. For example, the kitchen was used during the sessions by day hospice volunteers to prepare tea and coffee, and to wash up, so was screened only for part of the sessions (see Chapter 5). To prevent staff from using the day hospice space as a shortcut to the inpatient unit, signs were put up asking them to use other routes. I noticed that at least once during the sessions I observed these instructions being ignored. Furthermore, the room had windows overlooking the car park at one end and thus undertakers collecting bodies from the side entrance to the hospice cold room (section 4.5.6) were in full view.

On my first fieldwork session, a new member of hospice staff was spending the day in the session to find out what the service offered. I overheard the Senior Nurse who ran the session explaining that they closed the blinds to block the view when undertakers collected the deceased. Lawton (2000) reports a similar finding in her fieldwork in a day hospice setting. She describes how staff asked porters moving a body from the inpatient unit to the hospice mortuary when day patients were sitting outside to complete the task after the patients had gone home, thus maintaining 'the setting as a physically and symbolically bounded entity' (p. 69). Therefore, I argue that the practices employed to maintain a convincing performance of 'living' and hide hospice 'secrets', helped reveal the performance itself (Goffman, 1959/1990).

4.4.3 Décor and furnishings – domesticating the space

The 'furniture, décor, physical layout and other background items' are all part of the 'setting' (Goffman, 1959/1990, p. 32). I argue that in keeping with the hospice ideology of providing a 'home' for dying people (as I described in Chapter 2), the day hospice spaces were 'dressed' to invoke a domestic-like setting for the performance of 'living'. This reflects attempts to domesticate institutional spaces such as nursing homes (Hockey, 1999), although the institutional nature of the spaces was not always successfully hidden.

The day hospice room at Flora House was divided into a sitting area, a dining space and a kitchen, mirroring the living spaces designed for relaxing, eating and cooking typical of a domestic dwelling. Similar to an idealised living room, the room had large windows overlooking the hospice grounds and the lake. At one end of the space were a staff office and complementary therapy room, both enclosed, each with its own door. The staff room had windows overlooking the sitting area, suggesting staff surveillance of the patients and that, despite appearances, the space used by patients was not private.

In the sitting area a dozen high-backed easy chairs of the type used in nursing homes and hospitals were arranged around the edges of the space nearest the windows. Scatter cushions were placed on several of them and there was a small coffee table between every other chair. Lawton (2000) suggests that arranging patients in a circle may be a strategy to mask their physical deterioration since they do not need to move in order to converse with each other.

The dining area had three rectangular tables each surrounded by five or six dining chairs. This space was also used for craft activities. Shelves located behind the tables held craft materials and items made by the day-hospice patients, some partly finished. There was a low trolley with further craft supplies positioned against the wall. In the corner of this half of the space was a small sitting area with low easy chairs used for one-to-one talks between staff and patients. Thus, despite suggesting 'home', the furnishing and layout of the day hospice room belied its institutional purposes.

During the time I observed, the open-plan space was redecorated. On my first visit to the hospice, the Head of Clinical Services showed me round. She pointed out paint samples on the wall, explaining that the day hospice staff were choosing colours for the redecoration to make it '*less like an old people's home*'. On several occasions during the sessions I followed the forthcoming redecoration became a talking point between the staff, volunteers and patients. The senior nurse showed anyone who was interested the samples of paint colour and carpet that had been chosen, saying that it would '*make the area seem more homely*'.

This desire to disassociate the day hospice from 'old age' and its potential for association with deterioration and lack of hope, shows how the staff viewed the importance of the way the space was presented in achieving their goal of helping patients to 'live until they die'. As a result of the redecoration the colour of the walls was changed from a creamy yellow to dark teal on two 'feature' walls and cream elsewhere. The red carpet tiles, of the type often seen in offices, were

replaced with thick blue carpet in the lounge area and wood-effect laminate in the dining area. The flooring in the kitchen space, which was similar to that used in commercial kitchens and hospital sluice rooms, was unchanged. After the redecoration was complete, I noticed that the staff office had not been included. The nurses confirmed that there were no plans to redecorate it. The office space was not used by patients or volunteers during the sessions I observed. It was 'forbidden' space in that only people with legitimate access were able to enter making it what Goffman would call 'back' space. It was therefore not required to promote the performance of domesticity.

The day hospice room at Daisy Hospice, like that at Flora House, was divided into 'home-like' areas. In the half of the room nearest the courtyard garden, about fifteen easy chairs, similar to those at Flora House, were arranged in an oval pattern with small tables in between each pair of chairs, with two larger and lower tables in the middle of the space. It was easily possible to walk round the outside of the arrangement of chairs. At the other end of the room three dining tables each with four to six chairs were set out and also used for craft activities. In addition, as at Flora House, there was a smaller arrangement of low easy chairs and a low table in one corner forming a separate area where staff could talk with patients away from the main group. There were also some shelves holding a range of domestic books, including cookery books, novels, a 'book of days' (lists of historical events that had occurred on each day of the year) and 'scrapbooks' of different decades (1950s, 1960s, 1970s). The healthcare assistant who supported the sessions used these as reference material for the quiz she organised each week (described in Chapter 5). I never saw a patient reading them.

The most striking feature of the room was a frieze covering the long wall which separated the room from the original hospital building. This was of a summer meadow with larger-than-life-size pink and white daisy-type flowers and long bright green blades of grass. This evocation of nature, which I also saw in the hospice inpatient unit (section 4.5.2), could be interpreted as reflecting hospice 'back-to-nature' philosophy aimed at producing a 'natural' death (for example, Abel, 1986).

The day hospice facilities at Daisy Hospice included several rooms on the first floor above the inpatient unit used for complementary therapy, counselling and craft sessions. These were reached either by stairs in the lobby area by the side entrance to the hospice or by a lift in the

inpatient unit. Patients using these facilities who could not use the stairs were therefore forced to enter the inpatient unit.

To summarise, I have shown how the arrangement of spaces used for day hospice activities could be interpreted as emphasising the separation of life from death, its focus on 'living' and its contribution to keeping death a 'secret'. The way that the space was physically separated from the inpatient unit – the space for dying – emphasised the day hospice spaces themselves as heterotopic, since 'living' took place in a bounded space alongside that for dying. The spaces also revealed how hospice ideology was promoted in the invocation of 'home' and nature through the décor and furnishing of the spaces which established these as spaces for hospitality, which as I show in Chapter 5, was the focus of the volunteer role.

4.5 Inpatient Unit: Boundaries/forbidden territories

The hospice inpatient units, in which both living and dying took place, presented potentially challenging spaces in which to give a convincing performance of hospice ideology. As Seymour (1999) points out achieving a 'good death' requires considerable medical support despite the hospice movement's anti-medicalisation rhetoric. In this section, I discuss the inpatient unit spaces in light of the potential conflict between the functional 'clinical' part of the hospice's work and efforts to create the 'domestic, homely and calm place' required by hospice ideology (McGann, 2013, p. 75).

The section is in six parts. I begin by describing the overall layout showing how front and back spaces were juxtaposed. I then describe accessible 'domestic' spaces before moving to discuss the patient rooms where regions were blurred, before moving to the kitchen areas. Next, I consider boundaries/forbidden spaces, such as staff offices and the treatment room. Last, I discuss the most protected space of all, the cold room.

4.5.1 Layout: juxtaposing accessible and forbidden spaces

This section considers the overall layout of the inpatient units showing their division into front-stage 'domestic' spaces and back-stage clinical spaces, creating both accessible space and boundaries/forbidden spaces.

As I stated above, the two units contrasted architecturally. That at Flora House was housed partly in the original hospice building and partly in the extended parts of the building. It was a 'difficult'

space in which to keep front and back regions separate because of the way it was physically connected to the other hospice spaces. By contrast the inpatient unit at Daisy Hospice was purpose-built, and the potential conflict between 'domestic' and clinical regions had been largely dealt with by the designers. Comparing the two units helps reveal this difference.

As can be seen from the floor plan in Appendix F, the inpatient unit at Flora House was based along three corridors, forming an angled 'S' shape. Alongside patient rooms, front and back regions were juxtaposed along the first two corridors creating awkward boundaries and junction points. Therefore, to reach the patient rooms in the third corridor, furthest from reception, a visitor had to pass by spaces, such as the treatment rooms, nurses' office and sluice, not intended to be seen and therefore 'protected' in some way. How this was done is discussed below (section 4.5.5). The corridors were carpeted giving a feeling of domestic space, although the waist-height rail running the length of them, highlighting the needs of some hospice users, countered any homely feel.

The unit at Daisy Hospice (see Appendix H) formed a long rectangular space with entrances at both ends, one from the side entrance to the hospice (see above) and one from reception. The patient rooms were in a row along the back of the unit furthest from reception. The rooms took up around a third of the width of the unit, and the remaining two-thirds was laid out as 'domestic' space with a sitting and dining area overlooking the central courtyard into which there was a door (also accessible from the hospice day room – see above) and a small kitchen space for use by visitors. Flooring was used to designate the purpose of each space: the sitting area was carpeted while a 'walkway' space between it and the patient rooms was created by using a wood-effect laminate. A darker laminate flooring was laid in the patient rooms.

4.5.2 Accessible 'domestic' spaces

Similar to day hospice spaces, the accessible 'front' regions of the inpatient units invoked 'living' spaces found within a domestic home: sitting, dining and kitchen space. There were two such areas at Flora House, one a large room on the first corridor and the other an open space at the end of the second corridor, both with areas where relatives could make drinks. These spaces were fitted with domestic kitchen units, cupboards, sinks and fridges. Both rooms overlooked the hospice grounds and lake and had names invoking these outdoor spaces, in contrast to the functional names given to back-stage spaces.

At Daisy Hospice the open area of the inpatient unit also fulfilled similar 'domestic' functions. The furnishings referenced domesticity, with easy chairs, carpets and pictures on the walls, plus magazines, books, board games and toys. At Daisy Hospice toys were stored in two brightly coloured boxes labelled 'love' and 'peace', suggesting aspects of hospice ideology. Every time I visited there was a partly completed (and different!) jig-saw puzzle on the dining table in this space and vases of fresh flowers on the coffee tables. However, the clinical needs of the users of the unit were evident, for example, the electrically operated armchair placed against one of the windows which was labelled 'patient use only' and 'hygienically cleaned'. Along the walls between patient rooms were large corporate-style posters (roughly A0 size) of close-up photographs of flowers with the hospice logo in one corner, invoking nature in a similar way to the frieze in the day hospice space. At Flora House, patients and visitors were encouraged to take a close-up view across the lake outside using a telescope on a tripod placed near the windows of the open space at the end of the second corridor.

As noted by Worpole (2010), and in common with other UK hospices, both sites had a room designated as a 'quiet room'. These spaces were furnished with easy chairs and low tables and included some kind of memorialisation to patients who had died. At Flora House a 'tree' placed on a low table was hung with 'messages' from bereaved relatives. At Daisy Hospice a large book listing those who had died was left open on a stand. At Flora House I saw the room being used only once, by a doctor discussing a patient's condition with relatives. I found the room a useful place to make notes as it was reliably vacant. At Daisy Hospice I saw it being used once by relatives who were served tea there while waiting to view a deceased relative in the hospice cold room (described in Chapter 6).

These spaces, both placed at the edges of the hospice spaces, while referencing a 'sacred' purpose, reflected the ambiguity in the modern hospice movement about the place of religion in hospice care (Froggatt & Walter, 1995). Although Dame Cicely established the hospice movement as a Christian foundation and St Christopher's Hospice had a purpose-build chapel (du Boulay & Rankin, 2007), contemporary hospices now seek to present a more pluralistic front in an increasingly multi-faith and culturally secular age (Froggatt & Walter, 1995). However, ambiguity persists since death has traditionally been the business of religion providing solace to bereaved people and rites for those who are dying or dead (Kellehear, 2007).

Having described front accessible spaces, I now discuss the patient rooms where the distinction between regions was less clear.

4.5.3 Patient rooms – places of abode

Patient rooms were complex spaces, simultaneously front and back space depending on who was in the room, what they were doing and whose perspective was taken. A Goffmanesque interpretation suggests that, for clinical staff, they represented the front stage on which they performed the tasks they had prepared in back-stage spaces such as the treatment room. When personal or clinical care was being undertaken in the rooms, the spaces became back-stage space for the patients and ‘forbidden’ space for other actor groups, symbolised by the door being closed also ensuring patient privacy and dignity. At other times, for example when meals were served, the doors were left open. Hospice ideology may also offer an explanation for this. While anti-medicalisation rhetoric suggests that clinical activities should be hidden (Seymour, 1999), eating which, as I propose in Chapters 5 and 6, produced ‘living’ was here ‘on show’.

However, there are tensions within such explanations which are of interest. On my early visits to the hospices I was struck by the reality that the doors to patient rooms were kept open when the patient was clearly very unwell (that is, ‘actively’ dying¹⁴). Reflecting on this, I noted how my own expectations that dying people should not be visible were being challenged. At Flora House the practice meant that dying patients were on full view to anyone using corridor #1, for example to access the lift. If, as I argue in other parts of this chapter, the hospice is striving to sequester death, the doors should have been shut. Of course, from a practical clinical viewpoint it could be argued that staff needed to be able to see and monitor patients, with the ‘trade off’ of patients being seen by others an unwanted consequence. Another point of view could be that dying people might want to feel part of the life of the hospice, even in the process of leaving life.

It is also possible to offer sociological interpretations. For example, using Goffman’s notion of performativity, it could be argued that dying had become a ‘front’ stage activity and symbolic of hospice ideology of *not* hiding death. Using Lefebvre (1974/1991) to view the patient rooms as ‘places of abode’ also helps to explain this anomaly by referencing another part of hospice ideology: hospice as home. Thus, patients are dying ‘at home’. This fits with the fact that patients were the only group not required to sign in or to wear badges, both ‘front’ space symbols for

¹⁴ Although seemingly an oxymoron, the term ‘actively’ dying refers to the case where specific signs or symptoms suggest that a person is in the last days or hours of life (<https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/final-days/recognising-deterioration-dying-phase>, accessed 28 June 2019).

performers (Goffman, 1959/1990). Hospice as home could also be seen in the way the rooms were decorated.

Apart from two twin-bedded rooms at Daisy Hospice, all rooms at both hospices were singles. As Worpole (2010) notes, the provision of single rooms has removed the need to use the term 'ward' which suggests hospital rather than home. In the same way as other front-stage spaces, the rooms were furnished and decorated in a domestic style. The rooms had floral-patterned curtains and at Daisy Hospice bed covers of similar fabric. One of the volunteers at Flora House showed me that the bed covers were embroidered in memory of past patients, saying that she liked to see them on patients' beds covering the white sheets, as this stopped the patients looking '*Like [they were in] a morgue*'. The presence of clinical apparatus associated with hospital wards including beds on castors with adjustable side bars and wipeable mattresses, bedside lockers and overbed whiteboards belied the domesticity of the rooms, exposing the reality that this was a clinical environment.

Patients brought some personal effects with them. From their study photographing patients' bedside tables, Kellehear, Pugh and Atter (2009) suggest that hospice patients bring objects with them both to recreate their home environment and to emphasise their individuality. Following Twigg (2000) this suggests that they are resisting institutional depersonalisation. However, I noted there was little surface space for these objects, and staff and volunteers usually had to move them (which they referred to as '*tidying*') to find a space for meal trays and other items.

All the rooms had ensuite bathrooms with a shower, toilet and basin. However, patients with limited mobility were helped to use the corridor bathrooms which were fitted with a hoist and other safety equipment. At Flora House, the rooms were numbered (acknowledging popular superstition by replacing 'unlucky' number 13 with 12a), but at Daisy Hospice the rooms were named after local towns and districts. Since names rather than numbers are used in both hospital wards and bedrooms in some hotels, this aspect of the inpatient units could be interpreted as either un-institutional or institutional.

I argue that while patient rooms were spaces where aspects of hospice ideology were displayed, notably that of hospice as 'home', the reality of accommodating end-of-life care was not well concealed. As I explore in Chapter 6, these were both 'living' and dying spaces, front stage and back stage and, as such, created awkward 'junction points' for volunteers.

I now discuss the hospice kitchen spaces which, although not all physically located inside the inpatient units, formed an important part of the 'territory' accessed by volunteers, particularly those involved with inpatients. As I show, the designation of these areas in terms of Lefebvre's categorisation of spaces depended on the point of view of the actor group involved and on the volunteer role.

4.5.4 Kitchen spaces: 'accessible' and 'forbidden'

At Flora House the main hospice kitchen area comprised two parts separated by a waist-high serving counter across the width of the room. The space nearest the entrance to the hospice – the dining area – was 'accessible' space for staff and volunteers, although some volunteers, such as those involved in the day hospice, entered it only to collect the food for lunch. A sign on the door stated 'staff only' although the door was kept open. The space behind the counter provided areas for cooking; food and crockery storage; and washing up. It was accessible only by the cooks and volunteers who helped with washing up who wore a blue plastic apron to enter the space, changing into a red one to serve food to patients (see Chapter 6). While food hygiene is of key importance in institutional care, swapping aprons also acknowledged that volunteers were crossing a boundary and entering the 'special' area of the cooking space. The aprons thus served both a practical and a symbolic purpose.

In the dining area two tables were pushed together in the middle of the space and surrounded by chairs. These were used by staff and some volunteers for breaks. Against one wall were various 'kit' connected with providing food and drink: a water boiler, milk dispenser and ice cube maker. Against the opposite wall was a fridge stocked with milk used to supply the day hospice and the kitchen areas in the patient lounges which volunteers were responsible for restocking. Sandwiches and salads prepared by the cooks were stored in a chiller cabinet next to this. There was one window in each space and the lighting was poor, making it feel slightly shabby compared with the 'front' spaces of the hospice. The room was also used as a storage area for the various trolleys used to transport food around the hospice and on which used crockery was collected.

The counter dividing the dining and cooking areas was formed from heated cupboards accessible from the kitchen side, above which was a clear plastic 'sneeze guard'. The cooks (all paid staff) worked on the cooking side which was fitted with large-scale commercial catering equipment made of stainless steel. This material, not typically used in domestic spaces, gave the space an institutional rather than domestic feel. The gap in the counter which allowed access into the

kitchen also gave access to a small office used by the head cook for administration such as planning menus and ordering food, and a staff changing and locker area, off which was a single toilet. This area was also used by supper volunteers (and myself) to leave coats and other personal belongings. In the short corridor leading to the locker area were a large upright fridge and freezer.

During my fieldwork I spent a great deal of time in this kitchen area following volunteers. I saw people who were not staff or volunteers enter the space on only two occasions. On one of these a patient's relative brought a tin of biscuits as a gift for staff. She put her head round the door, explained what she had come for to the person standing nearest to the door and handed over the bag. On the other occasion, a relative came right into the space to ask the cooks for a second portion of a desert her relative had enjoyed. However, this was highly unusual, and I noticed that the volunteers I was with and a nurse sitting at the dining table stopped talking to watch what was happening, although did not say anything.

The 'main' kitchen at Daisy Hospice where food was prepared for both patients and staff was positioned within an area containing related 'back' spaces – a food store and office – connected to the hospice via a door which was locked when the cooks were not on duty and marked 'staff only'. Volunteers were not involved in this space, but stood in the doorway to hand over patient food orders or request extra supplies. Only if the cooks were absent did they venture into the kitchen space to leave the order on the nearest workbench.

At both hospices, therefore, the 'main' kitchen areas were 'protected' by other backstage areas, forming a kind of 'extreme' back stage. I noticed that special clothing was required to enter these spaces. The cooks wore 'whites' emphasising their professional identity among the other actor groups in the hospice (Rafaeli & Pratt, 1993) and their status as 'hygienic' workers. I rarely saw the cooks elsewhere in the hospice buildings. Conversations between cooks and others took place over the counters dividing the kitchens from the dining areas and other staff did not enter the kitchen spaces. Lupton (1996) points out that the preparation of food reflects cultural mores beyond simply satisfying nutritional needs. The back spaces of the hospice kitchens therefore hid the process of changing raw food into culturally appropriate 'meals'. In Chapters 5 and 6 I discuss the central role of food practices in the hospice production of 'living'.

At Daisy Hospice there was another smaller kitchen space accessible from both the inpatient unit and the day hospice room (see Appendix H). The volunteers used this space to prepare snacks and

drinks for patients, to use the dishwasher and to put away clean crockery. It formed both 'front' and 'back' space; although 'forbidden' to patients and relatives, the space was 'on show' as the door to the inpatient unit was kept propped open and the shutters which could be used to block the area from the day hospice room were closed only during the 'quiet' part of day hospice sessions (see Chapter 5). As it was visually part of both the day hospice and the inpatient unit spaces, the area's fittings suggested domestic rather than institutional space. These included floor and wall units with shiny white doors, a work surface, and domestic appliances: fridge-freezer, toaster and microwave oven. In the 'foot' of the 'L' was a large sink, a wall-hung water boiler and a domestic-style dishwasher. Other items betrayed the fact that this was institutional space, including a stainless-steel wash-hand basin in one corner and a tall trolley with slots for trays. The flooring was of practical vinyl, similar to that used for hospital wards and contrasting with the flooring in both the inpatient unit and the day hospice room. A waist-high counter divided the kitchen from the day hospice room, under which food items such as bread and tins of soup and fruit used by staff and volunteers to prepare snacks for patients were stored.

Patients and relatives occasionally stood in the doorway to this kitchen to ask something, such as about meal times or to change a food order. Thus, different actor groups in the hospice appeared to know where their institutional roles 'allowed' them to go. In Goffmanesque terms, patients and relatives, as 'guests' in the hospice, seemed to recognise which spaces were 'back' spaces and therefore areas not meant for them in their role as the 'audience'. Clinical staff at Daisy Hospice were barred from the inpatient unit kitchen while volunteers were on duty as the space was relatively small. However, a few, notably Bella, the second highest ranked nurse, regularly broke this rule to make themselves a hot drink. I interpreted this rule-breaking as demonstrating these staff's higher status compared with volunteers.

As I will show in Chapter 6, the kitchen spaces, particularly the smaller space between the inpatient unit and day hospice room at Daisy Hospice, were used by volunteers as 'back' spaces, in which they either prepared their 'performance' for patients or sometimes relaxed in.

In sum, the main hospice kitchen spaces were back-stage functional food preparation areas to which volunteers had limited access. The inpatient unit kitchen at Daisy Hospice was more ambiguous space being functionally back-stage but visually presented as a domestic front-stage space. All these areas were lightly 'protected' by physical barriers, doors which were usually

propped open. This was not the case for other 'back' spaces which are the subject of the next section.

4.5.5 Boundaries/forbidden 'protected' spaces

Areas directly related to clinical functions were kept locked, even when staff were using them, and required a fob or access code to open them. At Flora House they included offices for clinical staff (clinical director, senior nurse, doctors and staff nurses/healthcare assistants), the treatment room where drugs were stored and prepared, a door to an outside bin area and the door to the lower ground floor (described in the section on the day hospice space above). These were all in the first two corridors, mostly opposite patient rooms creating potentially awkward junction points. As I describe in Chapter 6 (section 6.3.2), volunteers who served meals were required to record how much patients had eaten. This involved entering the otherwise 'forbidden' space of the nurses' office. These volunteers did not have a fob to open the door so had to knock on the door to gain access. As this fieldnote shows, they were 'welcome' only for the time it took to fill in the notes:

While we [volunteer Katy and I] were talking [I asked Katy something about her role], a nurse I didn't recognise came in – Katy was sitting at the desk under the patient notes folders, and I was sitting in the chair next to the desk. The nurse took one of the folders from the desk we were at and sat at the adjacent desk to make some notes. ... After a short while, I said, 'We're in the way' and the nurse looked at me very pointedly and said, 'I didn't want to say anything'. My impression was that we were very unwelcome on the nurses' territory.

At Daisy Hospice, apart from the treatment room which was always locked, offices for the Nurse Manager and her deputy, and a social worker were situated at the end of the space. Other clinical staff including doctors, nurses and healthcare assistants, used an open space at the end nearest reception, similar to a nurses' station in a hospital ward. The space was raised slightly and surrounded by walls on three sides. Open-plan spaces are associated with 'openness', 'transparency' and 'non-hierarchical collaboration and inter-disciplinary work' (Hurdley, 2010, p. 46), so this arrangement of space appeared to reflect hospice ideology. However, although it gave the appearance of being an accessible space, I never saw anyone other than clinical staff and the two care assistant volunteers using it. A pillar obstructed access to some extent, and the ward clerk (a paid member of staff) sat at a desk arranged so that she overlooked the inpatient unit 'protecting' the space behind her which was filled with office equipment: desks with computers, cupboards, photocopier and shredder. A whiteboard containing patient information was on the

wall in the far corner of the space. It could not be read from the 'front-stage' spaces of the inpatient unit. This ensured that one of the most important 'secrets', confidential patient information, was kept hidden. The issue of volunteer access to patient information was important to my analysis and I discuss it further in subsequent chapters.

At both hospices other 'back-stage' spaces included sluice rooms and laundry cupboards. The doors to these were kept shut but not locked. At Daisy Hospice the sluice room was situated at the end of the space, hidden from view except from those using the nearest patient rooms. A door from the sluice room led to the outside bin area. The removal of rubbish (or 'dirt' in Douglas's terms) – a highly significant part of maintaining both domestic space and a hygienic clinical one – could therefore be sequestered. I saw these spaces at both hospices being used by the care assistants, volunteers and by the paid healthcare assistants.

In this section I have discussed some of the hospice 'back-stage' areas and how they were secured so that the tasks performed within them could be hidden. In palliative medicine the aim of clinical procedures is to 'control' the symptoms of disease. Lawton (2000) argues that they thus 'rebind' the patient's previously 'unbounded', and therefore taboo, body (p. 129). She suggests that it is this 'unboundedness' which the hospice is attempting to sequester rather than the fact of death itself, pointing out that the etymology of 'palliative' is from the Latin for 'cloak' (p. 144). Therefore, I argue that the 'back-stage' nature of spaces such as the treatment rooms and sluices becomes essential to maintaining the performance of 'living'.

I turn now to discuss what I observed to be the most heavily protected and hidden spaces, the rooms used to store patients' bodies after they had died.

4.5.6 Cold rooms – forbidden space and junction points

Both hospices had a cold room where bodies were moved to await collection by undertakers and where relatives could view deceased patients. These rooms therefore served as both mortuary and viewing room, reflecting hospice ideology to make death part of life (for example, Seymour, 1999) while simultaneously sequestering death. They were thus both back and front space and, in Lefebvrian terms, forbidden and accessible.

They were positioned away from the main flow of activity in the inpatient units yet still within the unit rather than in a basement as is common in hospitals (Howarth, 2007) reflecting hospice ideology of continuity of care (McGann, 2013). At Flora House the room was situated partway

along a corridor leading to some staff offices. At Daisy Hospice it was at the end of a short corridor at the far end of the inpatient unit. This position meant that it was as far from reception – the ‘main’ entry point to the hospice – as it was possible to be within the inpatient unit. The corridor also accessed a room used for staff meetings and the quiet room. I suggest that the positioning of the rooms in corridors not intended for patients, but used regularly by staff, also revealed the ambiguity of these spaces. They were still within the living space of the hospice, but away from the ‘living’ being performed in the inpatient unit.

The rooms were ‘hidden in plain sight’ with large plain wooden doors similar to those used for a store cupboard, and always kept locked. Unlike other ‘back’ spaces the rooms were referred to using a name unconnected with their function. I suggest that this indicates their importance as sequestered spaces. At Flora House the name included ‘Suite’, giving the impression of an expensive hotel room. At Daisy Hospice, following the pattern adopted for patient rooms, the room was named after another local district. I argue that, through the naming of these spaces, the patient continued to be defined as a ‘guest’ even after death.

I saw inside the room only once, when following a volunteer at Daisy Hospice (described in Chapter 7). The décor and arrangement of objects invoked domesticity. It was decorated in the same colours as the patient rooms, and the body lay on one of the patient beds with the same linen and cover. The hospice beds therefore served multiple purposes: for sleeping, as the site of clinical care, as a dying place, as transport to move patients and corpses, and as mortuary slab. The body was positioned to appear asleep, creating the ‘fiction of sleep’ as by morticians preparing a body for viewing (Howarth, 1996, p. 147). A small table with a jar of perfumed oil with sticks was placed next to the bed. However, the room was cold from the air conditioning designed to slow down the deterioration of the body.

Bodies of patients who died were moved to the cold rooms as soon as possible after death. I found it slightly shocking to arrive in the inpatient unit first thing in the morning after a patient had died during the night to find that the patient’s room was already entirely empty and being deep cleaned by staff. Although I understood the practical reasons for moving bodies quickly after death, including the need to prepare the room for another patient, the practice seemed to me unseemly and lacking in respect, as if the dead body was rubbish to be cleared away. However, the practice makes social sense if, drawing on Douglas (1966/2002), the dead body is seen as symbolic of pollution and therefore potentially defiling. From a Goffmanesque dramaturgical

perspective, it could be argued that the dead body was spoiling the performance of 'living' being promoted by the hospice.

Corpses were taken out of both hospices using 'back-door' routes. At Flora House double doors opposite the cold room led to a space outside the building where undertakers' vehicles could draw up out of sight of the patient rooms or 'accessible' areas, although it was overlooked by some staff offices and the nurses' office. At Daisy Hospice the cold room itself had double doors leading to a passageway along the side of the building to the car park via a tall wooden gate. I discussed how this was hidden from day hospice patients above in section 4.4.2. Both these routes meant that patients who died in the hospices entered and left the buildings by different doors. Worpole (2010) suggests that this creates an 'unresolved processional issue'. I argue that leaving by the front door symbolises a higher status than leaving by the back door, and therefore hospice practice at the two fieldwork sites could be seen as furthering the sequestration of death. Komaromy (2000) noted in her study of death in care homes that bodies were usually taken out by the most convenient exit, if necessary hiding the event from residents. She concluded that the body was in its 'most taboo state when it is a corpse *and* in the period surrounding its removal' [italics in the original] (p. 308).

I described above how 'living people were stopped' (Komaromy, 2005, p. 188) when a body was moved. I also saw this happen inside the inpatient unit itself, this time at Flora House. From my fieldnotes:

Then another nurse came up to me and said, 'We're just closing this corridor down'. She shut all the patient doors and shut the corridor doors and turned out the main lights – I waited the other side with the two housekeepers, and one of the healthcare assistants. One of them said, 'That's quicker than normal' [meaning usually they leave a longer interval before moving people who have died]. Another said, 'They probably want the room'. One of the housekeepers went to the window at the end of the chapel corridor to admire her new car, and we all looked too – two doctors came out of the Medical Director's office and one chatted with the housekeeper about the car.... I went back to see if they had opened the corridor – they hadn't – ... the housekeepers discussed cleaning room 2 [where the patient had died].

I was struck by how no one said anything about what had just happened. It was as if they were pretending nothing was happening, chatting about a car for example. Later, I wondered whether

this could have been a way of ‘relaxing’ ‘back stage’ away from the ‘emotional labour’¹⁵ (James, 1989) of dealing with dying patients and bereaved relatives. As Komaromy (2005) suggests, the sequestration involved in moving a corpse ‘makes real the liminality of its status’ (p. 308). Following Lefebvre (1974/1991), the inpatient unit temporarily became a ‘junction point’ where ‘access is forbidden except on certain occasions of ritual import’ (p. 193). In Goffmanesque terms, the space was temporarily ‘back’ space so that the business of the hospice could be hidden.

The task of moving bodies did not involve volunteers. A volunteer at Daisy Hospice told me that, when the staff ‘move’ someone who has died, they shut the kitchen door so that the volunteers cannot see ‘... *but you know what is going on*’, she said.

4.6 Summary

As I explore in the next four chapters, my data reveal that the key to the construction of the volunteer role is the life-death boundary and the way that the hospice ‘protects’ this. This chapter has therefore contextualised the volunteer role by showing how the configuration of the hospice buildings and their materiality demonstrate what I interpreted as a guarding role. The apparent contradiction between the hospice as a heterotopic place sequestering death and its ideology of ‘living until you die’ as expressed through hospice as home, highlights the ‘tension between a radical alternative approach to death and a wider society that wants to distance itself from death’ (Froggatt & Walter, 1995, p. 47). Drawing on Douglas (1966/2002) I suggest that the symbolic significance of boundaries explains the importance of keeping living separate from dying. In addition to highlighting the importance of the life-death boundary, the data in this chapter have also established volunteers as a separate actor group to staff. On entering the hospice, they sign in in a different place and have only their first names on their badges. They appear to be excluded from the vital monitoring role performed in (and by) the reception areas, have limited access to some ‘back-stage’ spaces, particularly those kept locked, and are not involved in what could be described as the ‘sacred’ role of moving bodies.

¹⁵ I describe the concept of emotional labour in Chapter 5 (Section 5.6).

Chapter 5. Day hospice – the performance of ‘living’

In Chapter 2 I discussed Hockey’s (1990) construction of living and dying in the hospice as a ‘biological continuum’ tracing the patient’s (and later his/her relative’s) journey from ‘living’ to ‘dying’ and back to living again (see Appendix A). In this chapter I explore the first part of this ‘journey’ – ‘living’ – which takes place in the day hospice. In Chapter 4 I described how the hospices promoted ‘living’ through physically defining separate spaces for day patients and inpatients. I showed how the day hospice spaces were ‘dressed’ to reflect hospice ideology of hospice as ‘home’ providing the ‘set’ on which a performance of ‘living’ could take place. In this chapter I explore how this performance was achieved, the institutional strategies this involved and the volunteer role in this. I employ two theoretical concepts in addition to Goffman’s ideas about ‘performance’: the idea of the volunteer role being constructed from boundaries, and the concept of hospitality through which I view the volunteer role as one of ‘host’ and the patient role as one of ‘guest’.

As I outlined in Chapter 3, together with an overview of the day hospice sessions, both ‘general’ and ‘professional’ volunteers are involved in the day hospice. The focus of this chapter is on the former but, where appropriate, I highlight differences between the two groups. Professional volunteers are the subject of Chapter 7.

This chapter is in five sections. First, I introduce some theoretical ideas about hospitality. Then I examine how the performance of ‘living’ was prepared, including looking at the ‘script’ for the sessions, the clothing worn by the different actor groups and how the ‘set’ was prepared. In the third section I discuss the issue of patient confidentiality which is also relevant to volunteers in other settings discussed in Chapters 6, 7 and 8. In the fourth section I begin the description of the ‘performance’ in more detail with the pre-session briefings given to the volunteers to show the operation of clinical boundaries between volunteers and staff. In the fifth section I describe ‘show time’ which includes a detailed consideration of a key part of hospitality, food practices. In the final section I discuss how the intrusion of death into the day sessions was dealt with.

5.1 Hospitality

Hospitality is a social process (Lynch, Molz, McIntosh, Lugosi, & Lashley, 2011) defining the relationship between 'host' and 'guest' (King, 1995) and the mutual obligations involved (Lashley & Morrison, 2001, p. vx). As I suggested in Chapter 2 the concept is embedded in the hospice movement since the Latin *hospes* means both host and guest (Stoddard, 1992). Telfer (2000) offers a simple definition of hospitality as 'the giving of food, drink and sometimes accommodation to people who are not regular members of a household' central to which is the concept of sharing one's home (p. 39). Within this meaning patients can be seen as hospice guests. King (1995) suggests that the concept has four attributes: it provides for the well-being, comfort and entertainment of the guest, typically involving food and drink; in return, guests must behave reasonably and have a social obligation to contribute to the relationship by being good company; the host knows what would be pleasurable for guests, part of which is a concern for guests' security; and the process involves social rituals around arrival and departure. Drawing on Goffman (1959/1990) Darke and Gurney (2000) point out that the roles of host and guest are 'performed' (p. 80). While the 'host' demonstrates that he is pleased to see the guest and that he is ensuring his guests' comfort, the guest responds by showing appreciation, avoiding making unreasonable requests and (usually) 'ignoring' deficiencies in the host's skills, such as burnt food.

King (1995) distinguishes two types of hospitality: private and commercial/public (p. 222). Private hospitality is (usually) located within the home, with 'host' and 'guest' having a pre-existing relationship through friendship or kinship. In commercial or public hospitality, for example that aimed at people travelling, these features do not apply. While in the private sphere reciprocal hospitality is common, in the commercial arena the guest is expected just to 'receive' with reciprocity expressed through payment (King, 1995, p. 227). Aspects of both private and public hospitality were apparent in the day hospice and, as I will show, while the volunteers acted as hosts, staff continued their clinical role.

Before describing the day hospice sessions themselves, I first discuss their preparation showing both how the stage was set for 'living' and how the volunteer role began to be constructed.

5.2 Preparing the performance

Drawing on a theatrical metaphor this section discusses the institutional 'script' for the sessions and two aspects of the 'set': the actors' 'costumes', which help to establish boundaries between volunteers and staff, and how the day hospice rooms were 'dressed'.

5.2.1 The script

Flora House day hospice provision centred around a twelve-week '*programme*'. Although this term suggests a course of study in the sense that participant start and finish together following a set curriculum, this was not the case. Patients simply joined and finished depending on need, and there was no particular agenda. The day hospice nurses explained to me that their objective was to show patients how they could live 'normally' despite their illness, for example, how patients could have a holiday by staying in a hotel that had special facilities. I suggest that the use of the term *programme* promoted 'living' by giving the impression that the patients would improve their ability to live after the programme was finished (and that they would finish, which was not always the case). The staff took pains to emphasise both to me and to prospective patients that they were not providing 'day care', explaining that they were not offering somewhere for patients to go once a week *ad infinitum*. '*Some older patients think we are a day centre, which we aren't*', a nurse told a prospective patient at a session I attended, reinforcing the hospice's aim to avoid any connection with old age which I also described in Chapter 4. Patients were required to sign a form to indicate that they understood the time limit on the service. A leaflet given to patients explained that their needs would be '*reviewed*' in order to continue attending and that they would be '*discharged ... if all aims and objectives have been achieved*'. I suggest that the use of such terminology associated with medical treatment also cast the programme as therapeutic. 'Drop-in' sessions were offered to patients who were discharged from the programme, allowing them to continue to use day hospice services on an *ad hoc* basis. They were also used by staff to introduce prospective patients to the service.

At Daisy Hospice, while the activities offered were similar to those at Flora House, the aim of the sessions was to provide respite care to allow carers time off. On two occasions a new patient arrived with a relative at the beginning of the session. From my fieldnotes:

The patients started to arrive One patient came through from the IPU with her daughter. The daughter asked the senior nurse if it was OK to stay for a while with her mother, and the senior nurse said that it was OK for five minutes but that they didn't like relatives to stay.

Later the senior nurse told me that it was important for carers 'to have a break'.

Although there was a nominal twelve-week 'trial' period, patients could attend for as long as they wanted (or their health would allow). Around half of the patients I met had attended the group for over a year. A fieldnote shows how the sessions provided 'day care' for patients whose illness was too advanced for them to benefit from other more 'active' sessions offered by the hospice, and that patients tended to 'progress' to the inpatient unit:

The senior nurse explained [to myself and a new member of hospice staff who was attending the session as part of her induction] that there weren't that many patients using day care at the moment with numbers being reduced by the other activities that the Day Centre offers [such as, exercise group, 'friendship' group, craft group]. However, there was 'natural wastage' as patients became sicker, moving to the IPU.

Here I have outlined the aims of the day hospice sessions at each hospice, showing how at Flora House the focus was on 'living' while, at Daisy Hospice, it was on respite care. As I outlined in Chapter 3 the majority of patients at Flora House had cancer while most of those at Daisy Hospice had other conditions. More patients at Flora House were therefore ambulant and appeared less sick than those at Daisy Hospice, although in reality their life-expectancy was shorter. Many of those at Daisy Hospice were at a stage of their illness where mobility and/or communication had become difficult. These factors affected the session and, to some extent, the volunteer role, and I draw comparisons where appropriate below.

5.2.2 The personal 'front'

An important aspect in the visual presentation of the 'set' is the use of clothing to present a 'personal front' (Goffman, 1959/1990, p. 34). In clinical settings nursing uniforms are highly symbolic (for example, Richardson, 1996), not only in terms of denoting status and professional identity within the nursing hierarchy (see, for example, The Royal Marsden NHS Foundation Trust (n.d.); Pearson, Baker, Walsh, & Fitzgerald, 2001), but also in providing 'symbolic protection against the polluting nature of their work' (Twigg, 2000, p. 150). At both hospices staff running the day sessions wore uniforms which were the same as those worn by their colleagues in each

hospice's inpatient unit, underlining their clinical rather than social role. However, during the drop-in sessions at Flora House staff wore street clothes, emphasising that their role during these sessions was not clinically focused (and therefore that the focus of the sessions was also not clinical). One of the nurses highlighted this connection between her identity as a nurse and her uniform in the following fieldnote:

The nurse helped a patient into her wheelchair – the patient asked her to look at her finger which had been injured – the nurse joked about doing proper nursing and that she should put her uniform on.

The general volunteers wore street clothes, and both hospices required them to dress in the same manner as non-uniformed staff, that is in a smart-casual style. Flora House had written guidelines for volunteers which specified garments considered unsuitable including 'frayed denim, shorts and mini-skirts, and sports clothing'. At Daisy Hospice, although there were no written instructions on dress specifically for volunteers, the following item was included in the checklist used by staff inducting new volunteers: 'Discuss appropriate clothing ... and explain Hospice [sic] dress code'. Dress serves as a mechanism for asserting organisational control and identity and can symbolise the core values and beliefs of an organisation (Pratt & Rafaeli, 1997). Therefore, the emphasis on looking 'smart' suggests that it was important for volunteers to appear 'professional'. A comment by a member of staff working with bereaved relatives which I report in Chapter 8 shows how the hospice provides a 'professional' service (section 8.5) and this may help explain the importance of appearance. However, the need for volunteers to look smart contradicts the way 'volunteer' was discursively positioned in tension with 'professional' by some staff in other settings (see Chapters 6, 7 and 8) where the characterisation of volunteers was closer to that reported by van Bochove et al. (2018) of volunteers as 'unskilled, authoritative and unreliable' (p. 8) which I outlined in Chapter 2 (section 2.6). I discuss the issue of the tension between 'volunteer' and 'professional' in Chapter 9.

Street clothes have various associations within clinical settings. Twigg (2000), for example, describes care workers who do not wear uniform being seen by clients as 'homely' compared with nurses wearing uniforms who are described as 'distant or professional' (p. 150). Volunteers and paid staff occupied day hospice spaces at the same time. Therefore, volunteers' street clothes emphasised their 'homely' role, while paid staff's uniforms stressed their clinical or 'professional' role. This demarked professional and clinical boundaries between them and paid staff. However,

street clothes can also be associated with settings where the focus is on rehabilitation from illness (Pratt & Rafaeli, 1997). Both patients and staff wear street clothes in psychiatric and rehabilitation units, but wear uniform in inpatient units (patients' bedclothes or hospital gowns being seen as uniform) (Pratt & Rafaeli, 1997). In her study of hospice patients, Lawton (2000) noted that staff and volunteers in the day hospice wore the same casual style as patients, which she interpreted as emphasising a desire to break down barriers between staff, volunteers and patients, supporting Pratt and Rafaeli's (1997) findings. Therefore, in light of these studies, the day hospice nurses' uniforms in both hospices in my study seemed incongruent with the production of 'living' in the day hospice sessions.

At Flora House the volunteers used a disposable plastic apron when serving lunch, while at Daisy Hospice the volunteers wore a tabard-style apron supplied by the hospice which they wore for the entire session, not just to serve food or clear up. The aprons were washed in the hospice laundry by another volunteer (who I did not follow as his role was not patient-facing) and were also worn by the inpatient unit general volunteers. In contrast to the general volunteers in their domestic aprons, the 'professional' volunteers (apart from the art therapist and spiritual care worker at Daisy Hospice) wore a clinical-style uniform which they supplied themselves. I asked volunteer complementary therapist Norma about the uniforms:

Norma said that it made them look 'more professional' and 'creates the relationship'. She explained that being in uniform got you out of difficult situations because it was clear where the boundaries were – if you were giving someone a massage they could get the wrong idea but if you are in uniform it's clear that it is a therapeutic service.

Similarly, uniform also helps professionals undertaking bodywork to cross boundaries 'safely' which otherwise would be prohibited in social life (Lawler, 1991; Twigg, 2000). I suggest that wearing a uniform was also part of the 'boundary work' (Gieryn, 1983) the professional volunteers undertook to differentiate their status as people supplying 'professional' skills. I outlined 'boundary work' in Chapter 2 and explore it in relation to these volunteers in Chapter 7.

To summarise, clothing signified clinical and professional boundaries between the general volunteers, professional volunteers and paid staff. Street clothes also emphasised 'living' and 'home', helping to position the general volunteers as 'hosts'.

I now turn to examine how the day hospice rooms were prepared for hospitality.

5.2.3 Dressing the set

Here I continue the discussion of the preparation of the performance area I began in Chapter 4. At both hospices the day hospice spaces were used in various ways by staff when not required for day hospice sessions, such as for meetings, as a rest area and, at Daisy Hospice, as a short cut between different areas of the hospice. Therefore, these institutional ‘back’ spaces had to be transformed into ‘front’ spaces before each day hospice session. Staff, who arrived about two hours before the sessions started, began this process, with volunteers joining in as they arrived, typically around half-an-hour before the session start time. I saw a volunteer set up the room from scratch on only one occasion, at Daisy Hospice when both regular staff members were on holiday. They had asked volunteer Tamara to set up the room. Tamara was a long-serving volunteer, having been involved with the hospice since it began (*‘since the portacabin days’* as a volunteer in the inpatient unit put it referring to the hospice when it first opened). Later in the same session Tamara ran the afternoon quiz session in place of the healthcare assistant. Involving Tamara in this way emphasised the importance of experience in the hospice. However, I did not ask staff why they chose Tamara so this is speculation. I revisit the issue of volunteer experience in relation to dealing with death and dying in Chapter 8.

Setting up the rooms resembled preparations made for a social gathering in a domestic space, adding ‘props’ (Goffman, 1959/1990) such as newspapers (and, at Flora House, bowls of chocolates), tidying – and sometimes cleaning – the room, arranging the furniture and even plumping up cushions. At both hospices, staff and volunteers played music on a CD player, usually ‘easy-listening’ classical or light pop music. Thus, the spaces were made ‘homelike’ (Lawton, 2000, p. 54). This fits with the aim of hospitality which is to ensure that guests *‘feel at home’* while being away from home (Hepple, Kipps, & Thomson, 1990, p. 309).

Props linked to entertaining the ‘guests’ were also included, although these were more institutional in nature. At both hospices an A3-sized flip chart on a stand that was placed at one end of the arrangement of chairs, onto which one of the volunteers transferred a word puzzle from one of the day’s newspapers (the same puzzle at both hospices). Throughout the day the volunteers encouraged patients to solve the puzzle when they were not involved with other activities. At Daisy Hospice clipboards and pens were placed on the small tables in the sitting area. These held two sheets of A4 paper headed ‘Day Services Chit Chat and Activities’. The first sheet listed trivia facts about current affairs and other items of (potential) interest, the second a quiz. This was prepared weekly by the healthcare assistant who told me that they were intended to

stimulate conversation among the patients, staff and volunteers, although I never heard this happen. The sheets also named the staff and volunteers on duty, and any visitors (including myself). The activities available were also listed: physical exercise, complementary therapy, spiritual and social support, craft. 'Have a wonderful day' was printed in large bold type at the bottom. The sheets were used as the basis of the session after lunch.

Statutory regulations meant that it was hard to ignore that these were institutional spaces with their attendant health and safety requirements. At Daisy Hospice the healthcare assistant was very particular that the chairs in the sitting area were arranged so as not to block the route to the fire exit. From my fieldnotes of a session where I was helping to set up the room:

The healthcare assistant said she wanted to keep clear spaces for patients in wheelchairs, and a clear space at the end nearest the tables, for access. She said several times, 'It's important'.

She repeated this instruction frequently during the sessions whenever chairs were added to the group or moved to accommodate new arrivals or to form smaller groups, such as when patients played board games or cards.

In sum, the day hospice spaces are prepared for their role in hosting the patients as guests, locating hospitality both in the home and in the commercial (institutional) sphere (King, 1995, p. 223).

In this section I have drawn on my data to show how the performance of living was prepared, first by examining the 'script', then through a consideration of the clothing worn by the paid staff and volunteers, and lastly I examined how the 'set' was dressed ready for the 'guests'. I have shown how clothing marked the 'general' volunteers as a separate actor group from 'professional' volunteers and staff through clinical and professional boundaries. While wearing a uniform helps nurses to cross personal boundaries not usually crossed in everyday life, all clinicians gain knowledge about their patients which also crosses personal boundaries, albeit not physical ones. Before describing the sessions themselves, I discuss how – and to what extent – volunteers had access to patient information. Since patient confidentiality is a Rubicon of professionalised clinical practice (for example, Sommerville, 2013), this matter was important in the construction of the volunteer role in both the day hospice and inpatient unit.

5.3 Patient confidentiality: the script

In healthcare settings maintaining confidentiality is part of the sacred trust between patients and clinicians (Cotton, 1989) and is a fundamental requirement of medical and nursing practice (for example, Nursing and Midwifery Council, 2018, p. 8). Disclosure of patient information is therefore heavily sanctioned by professional organisations (for example, BMA, n.d.). The need to maintain confidentiality consequently creates an issue about the involvement of ‘general’ volunteers who are not members of such a professional group. A revealing comment was made to me by a volunteer manager at Flora House:

“The biggest problem area is volunteers working alongside clinical staff who see volunteers as can’t be trusted regarding patient confidentiality.”

I argue that this perception of volunteers as untrustworthy, which draws on a discursive strategy of volunteers as unprofessional, was key in the construction of the volunteer role, and I draw attention to it several times during this thesis.

Both hospices made it clear in written documents that breaching patient confidentiality was a serious matter. Daisy Hospice’s volunteer policy document read:

‘Volunteers are required to treat as strictly confidential all information concerning patients, clients, or the Hospice The Hospice takes breaches of confidentiality very seriously and may terminate volunteer relationships where breaches occur.’

The volunteer policy document at Flora House stated:

‘All volunteers are required to sign a confidentiality agreement as part of their application [to be a volunteer]’.

That is, even before they have even entered the hospice, potential volunteers were made aware of the importance of confidentiality. Later in the policy document there is more detail, extending the sanctionable information to include anything about the hospice:

- *‘Volunteers have a duty to safeguard confidential information relating to patients, carers, other volunteers, staff, visitors and business details relating to the Hospice.’*

- *Volunteers are required to maintain complete confidentiality in respect of all their dealings with the Hospice. All requests for information must be referred to the Senior Management Team.*
- *Volunteers may have access to, or be entrusted with information that the Hospice has deemed confidential. Volunteers shall not at any time during or after the end of their volunteering disclose to any person, or make use of, such confidential information.'*

At Flora House volunteer job descriptions stated that *'Looking at patient notes or ascertaining information of a confidential nature'* was prohibited. At Daisy Hospice volunteer job descriptions stated that volunteers should be *'Able to maintain confidentiality'*.

An incident in the day hospice at Flora House illustrates how breaching patient confidentiality was swiftly dealt with by staff:

The senior nurse came over to the kitchen area where [volunteers] Tanya and Denise were, and gave them new job descriptions, saying that there were a couple of small changes and asking them to sign them. ... A short while later, Tanya and Denise were trying to find a pen to sign the new job descriptions. I asked what the changes were. Denise said it was to do with taking photographs – they are not allowed to. She had taken some photos of one of the sessions when people had dressed up [in a previous session], but the senior nurse had said that they shouldn't take photos of patients. This had been put in the new job description.

However, as the Daisy Hospice volunteer manager told me:

'There is a thin line between employment and volunteering – same human response [to help people] but there is no contract for volunteers, just an agreement instead. It's not a job so there's no contract to enforce. You can't sack anyone.'

This lack of legality – or possibility of recourse to a 'higher' power outside of the hospice – meant that volunteers were potentially 'uncontrollable' since the boundaries 'controlling' volunteers were less clear than for staff for whom the ultimate sanction was to lose their professional status. I explore the potential incommensurability of volunteers and paid staff and the tension generated in Chapters 6 and 7 and discuss the issue further in Chapter 9.

Having discussed how the issue of patient confidentiality was 'scripted', I now turn to describe how patient information was passed to volunteers in the day hospice.

5.4 Pre-session briefings

Before patients arrived staff held a briefing session for the volunteers about the patients expected to attend, similar to the 'handovers' held between consecutive staff shifts in clinical settings. These briefings simultaneously drew volunteers into a 'team' with the clinical staff and established boundaries separating volunteers from paid staff. I will also show differences between information given to the professional and general volunteers, which further mark the role boundaries.

Like the handover between successive shifts of clinical staff, the process at both hospices involved some aspects of ritual (Strange, 1996). They followed the same routine each week, incorporating 'standardised objects' (Helman, 1990), such as the senior nurses' clipboards, cups of tea or coffee, and also the use of particular terminology. Rituals serve several purposes including enhancing group cohesion (Helman, 1990). They are an important way of demonstrating the significance of an act (Goffman, 1959/1990), in this case of allowing volunteers to enter the professionalised territory of the paid staff through the 'release' of confidential information. I consider first how the rearrangement of space produced both the briefing ritual and revealed boundaries between volunteers and paid staff. I then describe the briefings themselves.

5.4.1 Back-stage spaces

At both hospices the briefings took place in a corner of the day hospice rooms where staff and volunteers rearranged the furniture (even though it had only just been arranged for the session) to create a rough circle of chairs. In Goffmanesque terms, these spaces formed a temporary 'back stage' emphasising the private nature of the information which was to be revealed.

Immediately the briefing was finished both staff and volunteers returned the chairs to their earlier positions. Except at Flora House, where one or two volunteers (and myself) used lockers in the staff office to store personal belongings, day hospice volunteers rarely entered the office spaces. When I asked the volunteers at Flora House about this, volunteer Nora told me that it was

used only by volunteers during sessions for carers ¹⁶ which were 'volunteer-run' with no staff present (Nora also helped at these). When staff were present the office therefore became 'forbidden' space for volunteers (Lefebvre, 1991). This delimiting of spaces emphasised both the 'back-stage' nature of the office space and the 'support' nature of the volunteer role in the day hospice. The paid staff used the offices as spaces to undertake administrative tasks connected with running the sessions, for example, taking telephone calls from patients. The door was often shut when I arrived even though no one was in the main day room:

I went down to the day hospice room [at Flora House] – there was no one in the main room although music was playing from the CD player – the nurses were in their office with the door shut.

The closed office seemed to me to be symbolic of the confidential aspects of patient information.

The briefings always took place in the temporary 'back-stage' spaces. In one session at Daisy Hospice the volunteers arrived and sat in the chairs intended for patients:

At about 9.40, the healthcare assistant came through and gave [volunteer] Rebecca some photos of her new grandson to look at. We all admired them. A short while later, the senior nurse came out and said, 'Ah, there you are; shall we move to the usual area?'

This fieldnote shows how volunteers and staff chatted while waiting for the briefing. It also demonstrates a staff hierarchy operated. While the healthcare assistant was chatting, the senior nurse called everyone to order. On other occasions the senior nurse also chatted with the volunteers:

[Volunteer] Rebecca arrived, said hello. The senior nurse asked her about her holiday and they had a brief chat. Rebecca gave her some sweets and chocolates she had brought with her, and the senior nurse put them on the central coffee table for the patients. Rebecca and I chatted – she had just been to Paris [Volunteer] Tamara arrived – she had a brief chat with Rebecca and the senior nurse....

¹⁶ I did not follow these sessions for reasons of time.

Researchers observing nurses' handovers report similar social behaviour, which enhances group cohesiveness (Payne, Hardey, & Coleman, 2000; Strange, 1996).

5.4.2 The briefing

The procedure for the briefings was the same at both hospices. It was usually given by the most senior member of paid staff on duty indicating the importance of the information about to be imparted and the role of staff as head of the day hospice team. This also created a hierarchy with volunteers. Not all the staff attended the briefings; they had already had their own briefing so the sessions were specifically for the volunteers.

The nurse giving the briefing read from a list of patients, using only the patient's first name. On one occasion at Daisy Hospice:

The complementary therapists wrote notes and asked for clarification of patients' surnames.

While Lawton (2000) argues that the use of first names within a social setting can help to break down hierarchical barriers, I argue that omitting surnames was used here to reduce the risk of volunteers breaking patient confidentiality in the community. This issue of names recurred when I followed a volunteer in the inpatient unit (see Chapter 6, section 6.4.1).

The nurse continued, giving the patient's primary diagnosis, using medical terminology, such as 'c.a. pancreas' or 'c.a. oesophagus', but no other medical details. She made a general statement about the patient's condition compared with the previous visit, typically limited to whether a patient was in a 'good state' or not. I was surprised by the use of medical jargon to describe patient's cancer diagnoses, but since none of the volunteers asked what it meant, I assumed that they had assimilated it (I omitted to ask). Two extracts from my fieldnotes show that the remainder of the briefings focused on aspects of the patients' requirements connected with hospitality, not only food and drink but also ensuring their 'guests' comfort:

The senior nurse went through all the patients, including those who couldn't come in that day, either because they were in hospital or on holiday. The senior nurse focused on what the patients liked and didn't like, any problems they had, such as finding it hard to hear above any background noise and needing to have all liquids thickened.

*The senior nurse went through a printed list of patients (looked like a landscape A4 table), describing any changes in patient condition since the previous week, or giving a brief overview of patients who were new or fairly new to Day Care, together with special requirements, focusing on issues with food – one patient needed everything to be the consistency of single cream and another couldn't eat anything hot and needed everything to be soft. The senior nurse said that one patient, who liked smoothies, should have an 'Ensure' first.*¹⁷

The briefings therefore focused on the hospitality-related needs of the patients, emphasising the volunteer role of 'host'. The use of medical jargon highlighted the clinical aspect of the sessions, and the paid staff role. Payne et al. (2000) identified that in their handovers, nurses defined patients in biomedical terms and used abbreviations and jargon. Since handovers are part of nursing culture, it may have been that the nurses were simply running the sessions in a way familiar to them and not aiming to acculturate the volunteers into nursing conventions. However, I argue that the briefings helped to establish a clinical boundary between the roles of volunteers and paid staff. I also noticed a difference in the information given to professional volunteers. For example, at Daisy Hospice, volunteer complementary therapist Steph returned after an extended break from volunteering for health reasons:

Steph was writing down the names. The senior nurse said that she'd say more to her about some of them – i.e. privately.

From time to time other members of staff and student nurses attended the sessions. They also were given more information than the general volunteers. At Daisy Hospice a nurse from the hospice's home service filled in for the paid healthcare assistant:

The senior nurse asked her name, explaining that she was terrible at remembering names. She said that she would give her a more in-depth briefing afterwards.

When volunteers arrived late for the briefing session staff did not reprise missed information or appear to make any effort afterwards to bring volunteers up to speed. At Flora House volunteers missed the end of a briefing when they went to answer the door bell to let patients in, leaving the

¹⁷ 'Oral nutritional supplement for people with, or at risk of developing, disease-related malnutrition'
<https://www.abbottnutrition.co.uk/products-and-services/Abbott-Nutrition-Products/ensure-plus-milkshake-style> [accessed 1/5/15]

volunteer complementary therapists and the paid staff to finish. This suggested that the briefing was a ritual which performed a purpose other than imparting information. As I have already suggested the briefings were important for social cohesion between staff and volunteers, which has also been noted in nurses' handovers (Holly & Poletick, 2013). I discuss in section 5.6 the role of the briefings in ensuring that death did not leak into the sessions.

Sometimes patients arrived early while the briefing was still underway, potentially intruding on a performance not meant for them (Goffman, 1959/1990). At Flora House a patient arrived early for a session:

One of the patients came in – 'Am I a bit early?' he said and went to sit down in the sitting area (it was 10.20) – the senior nurse continued with the report. He was not offered tea and coffee.

Similarly, at Daisy Hospice:

One patient arrived while the briefing was in progress. The senior nurse lowered her voice.

At Daisy House one of the patients frequently arrived early because of transport issues. He was also mostly ignored, other than by one of the volunteers who shouted '*Good morning!*' but stayed in her seat in the briefing area. Similarly, he did not intrude, staying in the sitting area. These 'welcomes' were in stark contrast to the ebullient welcome given to patients arriving during 'show time'. Using hospitality and performativity as lenses, the patients could be said to be performing their role of the 'good guest' (Darke & Gurney, 2000, p. 81) 'colluding' with the back-stage preparation of the performance by the staff and volunteers (Goffman, 1959/1990) by not making 'unreasonable' demands.

The ritual of the volunteer briefings therefore establishes the volunteers as part of a team with staff, but there was a clinical boundary between the staff and volunteers maintained through the control of patient information. This supports the literature discussed in Chapter 2 which highlighted the issue of volunteer access to confidential information (Andersson & Ohlen, 2005; Field-Richards & Arthur, 2012; Finn et al., 1987). Withholding patient information from volunteers can be used as a 'professionalisation project' by staff securing the boundary between themselves and volunteers (Overgaard, 2015, p. 386). This information is 'protected' by the professional rank afforded by the clinical role and possession of it can be associated with status within professional groups (Evetts, 2013). Since other hospice staff and the 'professional' volunteers were party to

more information (although I did not discover exactly what they were told), this created a hierarchy based on access to knowledge.

In this section I have examined how patient information was controlled with regard to the volunteers through the briefings which took place before each day hospice session. These involved elements of rituals and I suggested that the format was derived from nursing culture. The briefings allowed volunteers to step briefly into the professionalised territory of the paid staff but established clinical boundaries between them and paid staff. The additional information given to the professional volunteers revealed the different status of these volunteers, which I touch on again below and explore in more detail in Chapter 7. The nature of the briefings also emphasised the volunteer role as 'host' which I now consider in a detailed examination of the sessions themselves.

5.5 'Show time'

This section is concerned with the volunteer role in the production of 'living' through hospitality. It is in two parts. The first describes the sessions showing the volunteer role of 'host' and the staff's clinical role. The second considers food practices in more detail since these were central to the hospice's expression of hospitality and to the 'general' volunteer role, both in the day hospice and also in the inpatient unit which is the subject of the following chapter.

At the weekly day hospice sessions I observed at both hospices, patients were offered a variety of activities to fill the sessions. These included craft, quizzes and complementary therapy, as well as 'social' time with other patients and the general volunteers. In addition each patient spent time reviewing clinical matters with one of the staff which, at Flora House, as I have described, could also include setting goals, such as taking a holiday. Both hospices also offered a three-course lunch.

5.5.1 Hospitality – social rituals and entertainment

An excerpt from my fieldnotes from the start of a session at Flora House helps to set the scene, showing the change in atmosphere as the patients arrived:

The transport arrived – the healthcare assistant and the driver helped the patients in bringing a couple on wheelchairs. Immediately, the room exploded into welcomes – it was like a performance had started – [volunteers] Steven and Nelly are both very outgoing, friendly and warm. The

patients sat down and chatted to each other and to the [general] volunteers. ... The volunteers offered the patients tea and coffee, and offered biscuits. There were dishes of Roses chocolates on the coffee tables which the volunteers also offered round. Some of the patients took part in the flip-chart puzzle. The complementary therapists worked their way round the patients, asking if they would like a treatment, offering hand and foot massages, and reiki. Some of the patients wanted treatments, and some didn't think it was 'their thing'. One of the therapists took patients into the treatment room, and one did foot massages in the sitting area for a patient with mobility issues. The nurses also worked their way round the patients, taking them into a corner for a chat about treatment issues etc.

This fieldnote shows how the general volunteer role was focused on 'hosting', welcoming the 'guests', and offering refreshments and entertainment, while the complementary therapists and staff focused on their 'professional' roles. Staff also took charge of 'skilled' tasks such as helping patients with mobility difficulties to transfer to chairs. This required training which was not given to the general volunteers. From my fieldnotes:

The patients started to arrive – lots of commotion with a couple coming in on the [hospice] mini-bus by wheelchair – two patients had to be helped into chairs. One was asked to wait as the physio was going to come and watch how she moved from the wheelchair – this left her in the middle of the sitting area – a bit awkward, I thought.

I noted that the volunteers did not offer her refreshments until she was 'correctly' seated and thus 'taking part' in the session. Visser (2008/2017), in her work on the cultural meanings of food-related practices, suggests that offering tea and coffee is a cultural ritual 'welcoming' guests and indicating that hospitality has begun (p. 121).

At both hospices the volunteers moved patients' mobility aids. At Flora House these were stored in the corridor space outside the room, and at Daisy Hospice they were put against the long wall in the day hospice room (see Chapter 4). Separating patients from their mobility aids effectively 'trapped' them in their chairs; the aids had to be returned to their owners at lunch time so that the patients could move to the dining areas. However, removing these devices also promoted the home-like feel of the sitting areas. From her examination of hospice day care, Lawton (2000) suggests that day care was constructed so that patients' dependency and identities as 'objects' of 'care' (p. 65) were downplayed. She noted that staff, volunteers and patients drew on discursive

resources which positioned the patients as 'deserving' or 'special' rather than dependent (p. 65). This helped to mask patients' deteriorating bodies even though staff and volunteers 'took over' tasks for the patients (p. 66). Therefore, removing the aids could be interpreted as another way of promoting the performance of 'living'.

At Daisy Hospice, however, this performance was harder to promote compared with Flora House. The sessions started more slowly and had less of a 'party' atmosphere:

The first patient arrived and sat down at the end of the sitting area. Everyone got up [from the briefing] to start the day. [Volunteer] Rebecca noticed that the thermos jug they fill with hot water to make drinks was missing, and offered to go and get it from the kitchen together with the day's smoothie, which one of the patients likes to have. She came back with the items and also two clean tabard aprons for her and [volunteer] Tamara. [Volunteer] Melissa started to draw the day's word puzzle on the flipchart. The day started slowly, with patients arriving in dribs and drabs. Rebecca and Tamara offered drinks but it all took quite a while – no real dynamic feeling – several patients were left on their own.

Either a member of staff or a volunteer asked each patient what they would like to do during the session and indicated the patients' choices on a paper form. The forms were put in a pile on one of the dining tables and referred to from time to time by the staff and professional volunteers. The volunteer complementary therapists took patients who had asked for a treatment one at a time to the treatment rooms on the first floor. The volunteer exercise therapist took those who wanted an exercise session to a stationary bicycle which had been set up near the entrance to the car park. The paid staff worked their way round the patients in the same way as their counterparts at Flora House.

During this time at Flora House, patients and volunteers chatted. In one session I noticed that volunteer Steven and a patient clearly had a good relationship:

There was one patient I hadn't met before – although I remembered her from the Christmas party – [volunteer] Denise told me that she [the patient] and Steven frequently bantered together – I asked if they knew each other outside the hospice [since they seemed to friendly] and she said that they didn't, but that they'd just hit it off when the patient had started attending the Wednesday sessions.

Some patients talked among themselves while the volunteers engaged with those who were not included, mainly people with communication difficulties:

I noticed that the volunteers purposefully sought out patients [who were not engaged in a conversation] to talk to, rather than just joining in the most interesting conversation or being drawn towards the main 'action'.

At both hospices the general volunteers also involved patients in various entertainments notably solving the day's flip chart word puzzle. At Flora House this acted as something of an 'ice-breaker' with patients shouting out their answers creating a 'party' atmosphere. At Daisy Hospice, however, where a larger proportion of patients had communication difficulties compared with those at Flora House, the volunteers struggled to build up any kind of atmosphere, often completing the puzzle themselves with patients looking on. The paid staff encouraged the patients too:

Someone, I think the healthcare assistant, drew the day's word puzzle on a flipchart, and a couple of patients got involved, but there wasn't really any 'atmosphere' [by which I meant the overall mood remained flat and lacked excitement or exuberance]. Different people took over 'manning' the flip chart on and off through the day: the spiritual care volunteer, the senior nurse and the healthcare assistant.

At Daisy Hospice the paid staff also directed the sessions, suggesting when it was time to start any craft activities or encouraging the patients to play card or board games drafting in the volunteers and myself to make up numbers. While the senior nurse took on the role of talking to patients about clinical issues, the healthcare assistant ran some of the activities. From my fieldnotes:

The healthcare assistant ran the session making the fridge cake [served to the patients' carers at a special tea held later that day]. It reminded me of cooking with small children. The patients sat round the table with blue plastic aprons on. The healthcare assistant supervised standing up, and volunteer Tamara stood behind the circle. The healthcare assistant had put out some small electronic weighing scales with a china cereal bowl on top. She opened the pack of biscuits and one of the patients weighed them out She then said, 'What we're going to do now is put them in a plastic bag to crush them'. She opened a plastic bag and put the biscuits in it, then tied a bag tie round the open end, 'so they don't come out', she said. She split the biscuits between two bags. She gave them to two of the patients, giving one a wooden spoon and the other a large metal

spoon, and said to them that they should bash the biscuits to turn them into crumbs. A short while later I noticed that one of the patients was using a rolling pin Crushing the biscuits took some time as the patients mostly had poor motor control. The healthcare assistant then opened the bars of chocolate and broke up them up into a plastic jug. She took this into the kitchen to melt in the microwave – the microwave started to make a burning smell, so she took it out – Tamara suggested that she could put it in a bowl of hot water to melt it but the healthcare assistant said no it would have to be boiling water (ie continuously boiling). She said she would take it upstairs – a short while later she came back with it and asked one of the volunteers to get a bowl of hot water to keep the chocolate liquid while they measured the golden syrup. All this time the patients just sat around. Then it was time to weigh out the golden syrup. The healthcare assistant gave this job to one of the patients, who squeezed the syrup out into the bowl on the weighing scales. There wasn't enough, so the healthcare assistant went to the main kitchen to ask if the chefs had any more. The patients continued to sit round the table. The healthcare assistant returned empty-handed. The healthcare assistant then added the weighed syrup into the melted chocolate. Then she opened the packet of dolly mixtures she had bought and put them in the mixture. Then she added icing sugar, saying that it would help bind the mixture as there wasn't enough syrup, and poured the mix into the tin which she had already lined with foil. She put the tin in the fridge [in the IPU kitchen].

Cooking is an everyday activity in which these patients, who lived in nursing homes or relied on carers at home, could no longer take part. I suggest that by being involved in parts of the process of cooking, the illusion of 'living' could be produced. Later, when the fridge cake was served at the carers' tea, the healthcare assistant pointed out that the patients had made it.

The fieldnote shows how little Tamara contributed, although she had earlier helped gather the patients for the activity and put on their aprons. The patients, in their role as 'good guests', did not interrupt, contradict or show frustration. The only time during my observations when a patient showed some impatience occurred when there was insufficient time in the afternoon session to do the day's quiz, caused by two other patients taking too long to eat lunch. The quiz was an activity he particularly enjoyed. On that occasion, the paid staff acknowledged his irritation and, the following week, made a show of ensuring that there was time for the quiz.

Sometimes patients wanted to 'give something back'. At Daisy Hospice, the staff and volunteers ran a tombola to raise funds for the hospice and using donated items as prizes. The patients were asked to buy tickets. On one occasion a patient who lived in a nursing home won a packet of tea

bags which he could not use. He asked the volunteers and myself whether we would like them. Volunteer Tamara pointed out that they were not allowed to receive gifts from the patients. I also demurred. My impression was that the patient was disappointed not to be able to give something back.

Activities such as making the fridge cake, painting and craftwork, were routinely interrupted by staff and the 'professional' volunteers taking patients for clinical review or therapy. The volunteers and patients always acquiesced, even when it meant breaking up a card game, indicating the higher importance of these 'professional' tasks. This reinforced a clinical boundary between volunteers and staff. A fieldnote from a drop-in session at Flora House also illustrates this point:

A [new] patient and his wife arrived and were taken by one of the nurses into the sitting area. [Volunteer] Nora asked them if they would like a drink, and came back to the kitchen to make them. [Volunteer] Sue arrived and went over to the patient and his wife to introduce herself. She stayed to chat with them. Later, she came back to the kitchen [where myself and Nora were standing], and said that they'd started talking about 'paperwork' so she had come back.

Thus, Sue acknowledged that 'paperwork' – that is, potentially confidential patient information – was within paid staff's purview and not that of volunteers. In another drop-in session, when one of the nurses had finished talking to a patient, she came over to volunteer Ken and asked him to take over chatting with the patient. She went back into the staff office. Once I arrived early to follow a drop-in session. A patient's husband was talking to one of the nurses while his wife had an appointment elsewhere in the hospice. When I arrived the nurse told him that he could talk to me and got up to go back into the office. This demonstrated how staff's principal role was concerned with clinical (office-based matters), while the volunteers (and myself on this occasion) had roles focused on social matters.

The sessions ended when the patients' carers, volunteer drivers (Daisy Hospice) or mini-bus driver (Flora House) arrived. The volunteers brought patients their coats and mobility aids. They helped to push those in wheelchairs to the relevant transport and they said goodbye and 'see you next week'. Thus, the social rituals of departure expected of a host towards his guests were fulfilled. Once the patients had left, the volunteers tidied the rooms, wiping tables and chairs, and clearing up in the kitchen areas.

In this section I have shown how the volunteer role was largely concerned with the role of ‘host’ providing refreshments and entertainment, ensuring the comfort of the guests, and engaging in social rituals around arrival and departure. Paid staff were concerned with clinical matters and with directing the sessions to ensure that activities of ‘living’ were performed. To some extent the ‘guests’ colluded, mostly ‘joining in’ without complaint, thus ‘receiving’ the hospitality without reciprocity – a feature of commercial hospitality. However, aspects of more domestic-style hospitality could be seen in the relationships developed between the volunteers and patients. One of these was between volunteer art therapist Melissa and a patient with Parkinson’s disease which I describe in more detail in Chapter 7. I have shown how the sessions focused on ‘living’ by *doing: making something, playing a game, chatting or completing a quiz*. In the next section I demonstrate the importance of a key activity in the sessions, *eating*.

5.5.2 The role of food and commensality

Food is a cultural resource which is central to the practice of hospitality (King, 1995) and was the focus of much of the general volunteer role, both in the day hospice and in the inpatient unit (see Chapter 6). Eating has a special resonance in hospices since, as McInerney (1992) suggests in her sociological analysis of the meanings of food and drink in the last weeks of life, the dying process is made ‘visible’ through changes in eating patterns, such as reduced appetite or the adoption of a liquid diet. In my fieldwork in the inpatient unit I noticed ‘eating’ was symbolic of ‘living’ and ‘not eating’ symbolised dying (explored in more depth in Chapter 6).

The focus of hospice food practice and the central activity of the day hospice sessions was a three-course ‘home-cooked’ lunch. (The same menu was offered in the inpatient units and I describe it in more detail in Chapter 6.) Moisio, Arnould, and Price (2004) argue that ‘home-cooked’ is ‘discursively constructed as ‘made from scratch’’ (p. 373). At both hospices, food was prepared on site, although fewer items were made ‘from scratch’ at Daisy Hospice where food was provided by a contract catering company for whom the cooks worked. However, ‘home cooking’ is central to understandings of ‘home’ and ‘is understood to be personal and laced with intimacy and warmth provided by the cook’ (Hollows, 2008) thus evoking hospice ideology of ‘home’ and ‘family’.

The meal followed the traditional structure of a formal main meal in Western societies (Douglas & Nicod, 1974) with ‘starter’, larger main course comprising protein, carbohydrate and vegetables, followed by a sweet, typically fruit-themed, dessert. In the home setting such a meal would be

considered 'formal' and served mainly on special occasions, such as when entertaining guests or at Christmas (Douglas, 1975).

The volunteers played a key role in serving lunch following the rituals of a formal meal, including offering patients a printed menu and laying individual place settings (Visser, 2008/2017). Early in the sessions one volunteer showed each patient the menu, noted their choices and took the resulting list to the cooks in the main hospice kitchen. Closer to lunch time, one or two of the volunteers laid the tables with one setting for each patient who was 'eating'. Sometimes I helped with this:

After a while, [volunteer] Nelly got up to lay the tables for lunch and I offered to help. She counted up the number of places required, laying out table mats, cutlery and taking some glasses out of the cupboard, and a pile of paper napkins. She asked me to put a folded napkin in each glass. I did this, transferred them to a tray, and put one at each place. She took the salt and pepper pots out of the cupboard [in the kitchen area], together with small glass bowls containing sachets of other condiments: brown sauce, ketchup, salad cream. I put them on the tables.

At Daisy Hospice patients were offered an aperitif, in the form of an alcoholic drink before the meal, although in the time I observed, none took up the offer. The volunteers told me that this was usually the case. Volunteer Rebecca and one of the long-term patients performed a regular good-humoured routine where she offered him a 'drink', he 'accepted' by giving the thumbs up sign and she gave him a carton of fruit juice. (He had lost the ability to talk and drank using a straw.)

At Flora House two volunteers went up to the hospice kitchen to collect a heated trolley into which the cooks had placed the food, while at Daisy Hospice, one of the cooks brought a similar trolley into the day hospice room. He or she served the food required in the inpatient unit first (with the help of the IPU general volunteers which I describe in Chapter 6) and then pushed the trolley back through the day room stopping to leave the food for the day patients on heated trays on a table to one side of the room.

When the food arrived the volunteers and staff asked the patients to move to the tables, reuniting patients with their walking aids or wheelchairs. At Flora House all patients were helped to transfer to dining chairs, although at Daisy Hospice some remained in their wheelchairs. The volunteers at both hospices served the food onto individual plates, which they placed in front of

each patient in turn. Serving food was therefore a front-stage activity, meant to be seen as part of the performance of 'living'. Food at a formal meal in a domestic setting might be similarly served, with the host or 'mother' figure serving guests at the table (Visser, 2008/2017). However, only food items making up the three-course lunch were served like this. 'Light' or 'snack' Items such as baked potatoes, sandwiches and salads were pre-plated by the cooks, emphasising the status of the 'proper meal' in producing 'living' though the evocation of 'home' (Douglas, 1975; Hollows, 2008).

At Flora House lunch was the main occasion when staff, volunteers¹⁸ and patients came together. There was a great deal of good-humoured banter, always on general topics like holidays, the weather or upcoming events, such as the day hospice Christmas party. Lawton (2000) suggests that this type of behaviour has the effect of breaking down hierarchical distinctions between staff, volunteers and patients. However, I noticed that only the 'fitter' patients were involved. These patients usually ate at least two of the three courses of the main meal and sat together at one end of the arrangement of tables nearest the kitchen area. Those that ate fewer courses or less 'formal' food, such as a baked potato or a sandwich, sat further away and were less likely to be involved in the general chatter. At the time I observed, a patient with Parkinson's Disease who ate only a bowl of soup sat furthest from the kitchen. The healthcare assistant usually sat with him. The move from solid to liquid food can serve as a marker of disease progression (Seale, 1998a) and I noted how the patient with the most visible signs of deterioration sat furthest from those with the fewest signs.

The volunteers often encouraged patients to eat and sometimes covered up for them when they could not:

During the meal, the patient sitting near she apologised a couple of times that she couldn't manage her main course. Denise took it from her, saying that she needn't sit and look at it.

Thus, Denise enabled the patient to continue taking part in 'living' without the evidence of her 'failure' in front of her. Van Gennep (1960/1977) suggests 'the rite of eating and drinking together ...[is].. confirmation of a bond' (p. 29). Thus commensality – sharing of meals – is important as a

¹⁸ Staff and volunteers either brought their own food (as I did) or ate from the hospice menu for which they paid a nominal sum.

membership ritual (Seale, 1998a). This may explain why staff and volunteers put so much effort into ensuring that patients could take part in the meal.

However, some patients stayed in the sitting areas, for example, those who were fed via a PEG system.¹⁹ I noticed at both hospices that these patients stayed in the sitting area and 'dozed'. (I discuss the issue of 'medicalised' food in Chapter 6.) One patient at Flora House seemed particularly 'left out':

I noticed that one patient wasn't eating and stayed in the sitting area – he hadn't eaten the week before either, saying he was going out in the evening so didn't want anything. I don't know why he wasn't eating today. He went out for a cigarette, I think, and may have left early.

Despite the patients who did not take part in lunch, commensality was more successfully achieved at Flora House compared with Daisy Hospice. Here, volunteers and staff ate their lunch away from the patients in the staff room. They took turns based on an *ad hoc* rota organised by the healthcare assistant which, she told me, she organised to ensure that at least one member of staff and one volunteer were always in the day room. The volunteers served each patient their meal as they sat down and then served their next course without waiting for other patients at the same table to finish. Thus, although the diners were physically positioned as if they were taking part in a formal meal, they were in fact more like lone diners in a restaurant.

Unlike at Flora House, at Daisy Hospice several patients needed to be fed, and this task was largely undertaken by the volunteers. On one occasion I was drafted in to help. Patients who required feeding took some time to complete their meal, so volunteers took over from their colleagues to allow the latter to take their lunch break. This meant that a patient could be fed by two different people which, together with the fact that the volunteers often talked among themselves while feeding patients, seemed to dehumanise the patients. I felt awkward joining in the conversations because of this.

At both hospices the volunteers cleared up after lunch using the dishwasher in their respective kitchen areas, put everything away and wiped the tables. At Flora House the volunteers served

¹⁹ Percutaneous Endoscopic Gastrostomy allows a person who is unable to eat orally to be fed through a tube surgically inserted through the abdominal wall.

tea and cake towards the end of the session. Patients often declined cake, saying they were still full up from lunch. On one occasion a patient asked if a piece could be wrapped – party-style – for her to take home.

In this section I have shown how food had a central role in producing ‘living’ through the ‘socializing [sic] power’ of food (Shilling, 2005, p. 152). I have shown the volunteer role in this: ‘hosting’, serving food and clearing up, thus promoting ‘living’ by ‘helping’ patients to keep their place at the table. Food therefore had symbolic significance in the hospice in promoting ‘living until you die’. It is therefore perhaps surprising that those lowest in the social hierarchy, the volunteers, had such a key role in serving it. As I show in Chapter 6, food-related tasks in the inpatient units were covered by those at the bottom of the clinical hierarchy in the absence of volunteers. This delegation of food-related tasks to those of lower status is discussed by Heaven, Bamford, May and Moynihan (2013) who, following James (1992), suggest that tasks connected with food in hospital settings have low status since the professionalisation of nursing has led to ‘domestic’ or non-‘technical’ tasks, such as feeding patients, being delegated to lower status workers. They also suggest that the use of volunteers to help feed patients further ‘trivialises food work’ (p. 639). I argue that this produces a contradiction between the importance of food practices in producing ‘living’ in the hospice and the ‘downgrading’ of food because it is not part of the clinical work of the hospice. It also suggests the pervasiveness of the medical model. These issues also arise with regard to volunteers in the inpatient unit (Chapter 6) and I discuss them further in Chapter 9.

As part of the hospice ‘project’ concerns making death ‘safe’ (Douglas, 1966/2002) and death is a fracturing of society (Seale, 1998b), I now consider how death was ‘resisted’ in the performance of ‘living’ and the volunteer role in this.

5.6 Promoting ‘living’ by resisting ‘dying’

Part of a host’s responsibility is to ensure guests’ security and comfort (King, 1995), and I argue in this section that in the day hospice this involved ensuring that death and dying did not leak into the sessions. Thus, the performance of ‘living’ could continue without interruption. As I will show this did not mean that the reality that patients became sicker and died was unacknowledged. As volunteer Nora explained, *‘They [the patients] know why they’re here and we know why they’re here, so you don’t have to do that bit of the journey; you do the next bit with them’*.

Whereas in their everyday lives patients may hide aspects of their illness to spare the feelings of family and friends, hospice day services provide a place where they can 'feel normal' by spending time with others in a similar position to themselves (Lawton, 2000, p. 53) allowing them to discuss topics which would 'normally' be taboo. Volunteers Denise and Tanya both told me that they had been involved in patient conversations about funerals and coffins, for example. This suggests that patients collude with each other in 'resisting' the performance of 'living'. Such talk has been noted by other researchers, for example, Langley-Evans and Payne (1997). Although I did not hear such topics discussed in the day hospice, a patient at Daisy Hospice told the volunteer I was following in the inpatient unit that she wanted her coffin to be decorated with painted fingernails. However, a tacit acknowledgement of death occurred during a craft session at Flora House where patients were making prints of their hands in clay. Although the significance of these was never articulated by staff to the patients, the patients 'understood' that this was a legacy project. For example, one patient announced that she was making two clay hands, *'One for each of my children'*. So, I argue here that death was being acknowledged, but from within the safety of a performance of living.

Occasionally the performance was exposed. For example, a prospective patient attended a drop-in session at Flora House. One of the nurses gave her the leaflet describing the service. This included the fact that the 'programme' was twelve weeks' long. From my fieldnotes:

'Twelve weeks – how long's that then?' she said. The nurse said, 'Three months'. 'They've given me six months: I'll be dead by then!'. There was an outburst of (embarrassed or awkward?) laughter.

Thus, by acknowledging the potential brevity of her remaining life, this patient suddenly exposed the life-death boundary potentially ruining the performance of living. Her 'transgression' was covered up by laughter. Patients were not 'supposed' to die during the twelve-week programme with its focus on 'living' and goal setting. Predicting death is an important strategy in producing a 'good death' and thus controlling its uncertainty (Komaromy, 2002). However, a systematic review demonstrated how poor clinician estimates of palliative care patients' prognoses are (White, Reid, Harris, Harries, & Stone, 2016).

Inevitably patients died and, since they attended the sessions over a period of time, they developed social relationships with volunteers and staff. Therefore, the deaths of former patients,

as well as current ones, could 'disrupt' the sessions. Death therefore had to be 'managed'. In a quiet moment in a drop-in session at Flora House I asked the healthcare assistant about her role accompanying the driver of the hospice mini-bus in picking up day hospice patients who otherwise had no transport. She explained how she used the time:

... to chat to patients to find out how they are and that this is helpful as it is relatively private. For example, four patients who had attended the Wednesday sessions had died in recent weeks, and it was useful to let patients know this before they arrived at the centre where other patients may already know. They could then have the day in the day hospice which aimed to be positive before going home. She thought this was helpful.

Lawton (2000) also noted how day hospice staff told patients individually when a patient (or former patient) had died, rather than announcing the death to the whole group, and how this practice 'served to keep the topic of death at the fringes of the group to enable it [that is, day care] to be sustained as a 'living' space' (p. 70-71).

Volunteers were told of patient deaths by staff during the briefing sessions:

The nurse worked her way down the list of patients who usually attended the session. She reached one patient and said that he had 'passed away'. Steven said, 'What?!'. 'He's died', she said. Another volunteer said, 'He's only been coming a few weeks'. The nurse explained what had happened. She said that she would tell MP1 [one of the patients who had been friendly with the patient who had died]. There was a bit of a silence before she moved on to the next patient. I heard no mention of the patient who had died all day.

In another briefing:

Steven said he'd seen a patient's obituary in the local paper, and he also had seen that a patient he'd met at the Christmas party who came to the day hospice sessions on Tuesdays had died – the nurse acknowledged the first death (obituary) but skimmed past the second – may be because the 2nd patient wasn't known to the other volunteers?

The first fieldnote shows how the death of a current 'programme' patient was 'untimely' and thus 'out of order' (Douglas, 1966/2002). The fieldnotes also show how death was 'dealt with' by staff as far as the volunteers were concerned by acknowledging it but not dwelling on it.

Maintaining the illusion of 'living' could be difficult when the patients brought 'dying' with them into the sessions. The following two excerpts from my fieldnotes of sessions at Flora House show how the volunteers were involved in preventing death and dying from rupturing the performance of 'living':

While we were .. in the sitting area [after lunch while the craft session was being set up], one of the patients received a text from another patient with bad news about that patient's condition – she read it out to the healthcare assistant and [volunteer] Nelly (it was the result of a scan). The patient was clearly upset by it – the healthcare assistant and Nelly comforted her.... Later, I had a chat with the healthcare assistant – she mentioned ... the text the patient had received, saying that the patient didn't need it [i.e. someone else's bad news]. I said, that they obviously got to know each other. She said what was going on was 'very complex' and changed the subject.

... a patient ... came in and [volunteer] Tanya greeted her. She stopped by the table nearest the kitchen area and Tanya asked if she was OK. She said she wasn't and would just stand there for a minute. Then she moved to sit down in her 'usual' seat (she 'always' sits in a particular place for lunch and puts her scarf and bag there when she arrives). Tanya sat down with her – the patient burst into tears and Tanya sat with her for some time talking to her. After a while, the Chaplain arrived – he sat down next to the patient and gave her a hug – they chatted for quite some time.

These were the only occasions when I witnessed any outward show of emotion in the day hospice sessions. This shows how the performance of 'living' was managed through the process of 'emotional labour' (James, 1989), that is dealing with the emotions of others with the 'goal of maintaining harmony within a social unit or workplace' (Lupton, 1998, p. 127). The concept was coined to refer to the commodification of 'emotion work' (Hochschild, 1979, 1983) whereby employees are required to express certain emotions as part of their roles. I discussed with volunteer Ken how he managed the emotional aspect of his role:

He told me that he thought he may be quite a 'cold' person as he could make changes in his life [referring to a previous conversation when he had told me about himself] without getting emotionally entangled, and that's why he found it OK working 'here'. He asked me how I was finding being in the hospice - he said something like 'being in this kind of place' - , and I said that I'd had some experiences of hospices before, but that this was much more real.

This fieldnote shows how Ken recognised that the hospice was an emotionally challenging place, but how he 'dealt' with it because of his ability to detach himself from another's emotion and how he saw that other people – myself in this instance – may not find it so easy. I noticed how warm and friendly he was in his encounters with patients, striking up relationships with them easily.

However, this conversation illuminated the importance of volunteers being emotionally robust which was recognised by staff as also important. In an informal chat with one of the nurses at Flora House, she told me that the senior nurse who ran the day hospice had interviewed several volunteer complementary therapists but that she did not think some would be able to cope with the environment: 'it's important to be able to protect yourself', she said. She told me that she and the other day hospice staff only worked three days a week (the manager worked four days) in order to have a 'good work-life balance'. The senior nurse told me that she always asked potential volunteers how they intended to 'look after themselves'. It may be that only those who are mentally strong volunteer (Morris et al., 2013) since research shows that stress and burnout amongst hospice volunteers are low (for example, Brown, 2011b). One way that staff and volunteers showed that they did not become emotionally involved was to attend patient funerals only rarely. In the time I observed this occurred once:

During lunch the senior nurse returned from the funeral..... [later] They discussed another patient who had died ... the healthcare assistant told them that the service sheet from his funeral was in the office and they could have a look at the photo of him, which was very good.

This was the only occasion I witnessed the volunteers and staff discussing a former patient's death. I asked volunteer Nora whether she attended patient funerals and she told me only rarely, the last occasion being three years previously for a patient whose relatives she had known well since they had also used the carers' sessions with which she was also involved. She could not remember the name of the patient and later in the session:

The nurse said, 'I can say this as there're no patients – what was the funeral you were trying to remember?'

This fieldnote shows volunteers and staff acknowledging a death between themselves but how the nurse had deliberately avoided discussing it when patients were present, thus promoting the performance of living.

In this section I have shown how death, which inevitably intruded on the day hospice sessions, was contained in order for the performance of 'living' to continue. I have touched on the emotional management the volunteers required to do this and on how staff and volunteers 'protected' themselves by not attending patient funerals.

5.7 Summary

This chapter has focused on the 'general' volunteer role in the day hospice setting, showing how the role was distinct from, but nevertheless complemented, that of staff. To contextualise the volunteer role I drew on Goffman's notion of performativity to highlight how 'living' was promoted in the day hospice sessions through the written information given to patients, how the different actor groups dressed and how the day hospice spaces were furnished and decorated. I showed how the access to confidential patient information created a clinical boundary between volunteers and staff. The production of 'living' continued through hospitality practices, which were the focus of the volunteer role. Part of hospitality is to ensure the safety of guests and I showed how volunteers support staff in monitoring the life-death boundary to prevent death from leaking into the sessions.

As part of 'setting the scene' regarding the issue of patient information, I quoted the volunteer manager at Daisy Hospice who told me that '*There is no contract for volunteers to enforce*' (emphasis added). I suggested that this creates a less clear boundary around volunteers compared with staff since volunteers have no professional body to which the hospice can appeal in cases of misconduct. Drawing on Douglas (1966/2002), this casts volunteers as potentially 'dangerous'. I develop this theme in subsequent chapters.

Chapter 6. Inpatient unit volunteers: isolating boundaries

In Chapter 5 I showed how the volunteers in the day hospice took on the role of ‘host’ to produce a performance of ‘living’ through the enactment of hospitality rituals. In this chapter I explore the role of volunteers in the inpatient unit in a continuation of this performance which, as I will show, in terms of Hockey’s (1990) ‘biological continuum’ (see Appendix A) is maintained until the patient is deemed to be ‘dying’. However, whereas the day hospice volunteers performed a role which largely complemented that of staff, as I will show from my data, the inpatient unit volunteer role was more clearly defined within boundaries. I will show how volunteers were kept away from death and dying and how other boundaries – temporal, spatial, organisational and clinical – isolated volunteers from other actor groups. As in the day hospice both ‘general’ volunteers and ‘professional’ volunteers were involved. This chapter is concerned solely with the former while the latter are the focus of Chapter 7.

Since the volunteer role was almost entirely food-related (serving meals and drinks, clearing up and restocking supplies in the patient-relative kitchen areas), I begin the chapter with an overview of the meals offered to inpatients. This summary also shows how the hospices in the study used meal structure to produce ‘living’. I then provide a vignette of a volunteer shift to which I refer in the remainder of the chapter. Next, I consider the volunteer role in (re-)producing ‘living’ through hospitality, before focusing on four issues from the vignette to illustrate the boundaries mentioned above in more detail. In the last part of the chapter, I continue my analysis of the patient rooms which I began in Chapter 4 to examine the volunteers’ relationship with these spaces which are both sites of hospitality and of death and dying.

6.1 Hospitality through meal structure

In this section I describe the meals offered to patients at each hospice to continue the ‘story’ I began in Chapter 5 about the hospice use of food to produce ‘living’. I show how hospice food reflected the ideology of hospice as home. I draw on Douglas’ analysis of what constitutes ‘proper’ meals (outlined in Chapter 2) to argue that food practices, in particular ordered systems such as meal structures, show how ‘mealtimes are regimes [which] serve to reinforce ontological security’ (Seale 1998a, p. 158).

As I described in Chapter 2, drawing on Douglas and Nicod (1974), traditional British food practices involve three meals a day with specific food items served in those meals. The meal structures therefore reflected 'traditional' British food, so were likely to be culturally familiar to most patients even if not a realistic reproduction of their domestic lives. In both hospices patients were offered breakfast in the morning, a three-course 'formal' lunch at around midday and a two-course 'supper' in the early evening. Tea and coffee were served between breakfast and lunch, and again between lunch and supper, with biscuits in the morning and cake in the afternoon. Thus, what Douglas and Nicod (1974) referred to as 'food events' (p. 744) occurred in an 'ordered pattern' (Douglas, 1975, p. 251). I argue that this ordering was part of producing 'living' in the hospice even though, as I will show, few patients ate all the meals.

The menus were 'traditional' reflecting the meals typically offered in British commercial hospitality establishments, such as hotels. Breakfast included a choice of cereals, porridge, toast and cooked items (bacon, sausages, eggs and so on) (described on the Daisy Hospice menu as 'full English breakfast'). Flora House also offered tinned grapefruit segments and a choice of fruit juices. Lunch was the main meal of the day at both hospices which is no longer the typical pattern in UK households. I did not ask why the main meal was served at lunchtime, which is common practice in other residential care-based establishments in the UK such as hospitals and nursing homes. I noted that fewer catering staff worked in the evenings so the reason may have been to reduce costs. The menus reflected 'tradition', nostalgia and formality typical of an institution and of formal meals in the home: a first course of soup or small salad (also grapefruit segments and fruit juice at Flora House) followed by a 'main' course based around 'traditional' 'British' dishes, such as fish pie, cottage pie and cauliflower cheese, as well as popular 'foreign' dishes such as lasagne and stir fry. The main course of Sunday lunch always included roast meat. At Daisy Hospice the vegetable accompaniments to the main course were elaborately described, such as 'chipped potatoes', 'parsley new potatoes' and 'carrot roundels'. Desserts included steamed puddings served with custard, chocolate brownies, cheesecake and peach melba. At both hospices 'supper' involved a 'light' but hot first course, such as smoked haddock and poached egg, fish fingers, Welsh rarebit, ham, egg and chips, soup or omelettes, and a dessert, usually non-home-made items such as yoghurt, jelly and ice cream, and tinned rice pudding. Following Douglas and Nicod (1974) hot food denotes a 'meal' rather than a snack, so the hospice can be seen to be providing 'three good meals a day'.

In this section I have described the meals and snacks offered to patients in the inpatient units. At both hospices the inpatient volunteer shifts were organised around these meals or food events.²⁰ The requirement to serve biscuits in the mid-morning drink and cake with the afternoon drink was even ‘scripted’ in the job description for the morning and afternoon volunteers at Flora House: ‘Offer patients and visitors beverages and biscuits (am) and cakes (pm)’. I argue that food practices provided a cultural script within which order could be maintained and chaos averted (Douglas, 1966/2002). This ‘script’ was particularly ‘visible’ at Daisy Hospice, where volunteers laid the patients’ meal trays with a large paper doily before adding cutlery, a water glass and a folded paper napkin. I suggest that setting the tray in this way made the ‘food event’ appear like a formal meal, regardless of what the patient had ordered, with the doily standing in for a tablecloth. Laying a table for a meal promotes order and control and so produces ‘living’ (Douglas, 1966/2002; 1974; Visser, 2008/2017).

In the next section I provide a vignette of a typical supper shift at Flora House. It is taken from the first shift I undertook with volunteer Katy. Her usual partner on this shift, Ruth, was on holiday. It should be read in conjunction with my description of the kitchen space in Chapter 4.

6.2 Vignette: a supper shift with Katy

A supper volunteer came in and went straight into the kitchen. I didn’t realise who she was. She whizzed into the kitchen and got straight to work at the washing up machine²¹ (or so it appeared – she must have hung her coat up). Cook Mandy introduced us. Katy was happy for me to help and I put on a blue plastic apron and helped put things away. During some of this time Mandy was cooking an omelette. After about fifteen minutes Katy and I had a break, making tea. Katie helped herself to cake from a plastic container on the dining table. This was leftover cake that had been made by the cooks for the patients and visitors. Mandy joined us at the table, and we chatted together, sharing personal information in a similar way to work colleagues. Office and clinical staff

²⁰ At Flora House, part of some volunteers’ role also involved tasks in the hospice laundry which I will not describe both for reasons of space and because they did not involve patient-facing tasks.

²¹ Of the type found in commercial kitchens fixed to a draining board. Dirty crockery is loaded onto plastic trays and pushed into the machine and a ‘lid’ lowered for a washing cycle of around 90 seconds. The lid is then raised and the tray pushed along so that another tray can take its place. Items dry quickly because of the temperature used in the machine.

came and went bringing used crockery back to the kitchen or making themselves hot drinks. At 5.30 pm Katy and Mandy started serving supper.

Mandy had already prepared the patients' supper trays loading them onto a tall trolley, sliding each tray into a slot. The trays were laid with cutlery, a paper napkin, and the patient's first course or sandwich. She gave Katy a clipboard which held a form pre-printed with the patient rooms against which she had added patient names and supper orders. The day's menu options were written at the top of the paper, including the soup variety (tomato) and sandwich options (beef, tuna and cucumber) and the hot dessert option (rice pudding). The main dish was not included which Katy later told me, when I asked, was because none of the patients was having a main meal.

Katy added two columns to the list, headed 'T' and 'C', which she told me was to add tea and coffee orders. She also explained that she was required to note down how much the patient ate and pointed out that she had added 'B' next to a patient who needed a beaker to drink from, taking this information from the kitchen whiteboard. The cook pointed out a patient who was PEG-fed and told Katy she may have to ask a nurse about this.

We started to head out of the kitchen when she remembered we had to change our aprons. She explained that a blue apron was worn in the kitchen and a red one in patients' rooms so that we did not contaminate the kitchen. (Later I discovered that patient rooms were considered 'dirty'. For example, the afternoon volunteers offered a cake 'sample' plate to patients and visitors to show the cake selection for that day: one piece of each type of cake was arranged on a side plate and covered with cling film. Anything taken into patient rooms was thrown away. A similar system operated at Daisy Hospice.) Katy tore two red aprons from the roll kept in the dining area, giving me one. We hung the blue ones on some pegs just inside the kitchen, then headed out into the IPU corridor with the trolley.

Katy worked her way down the inpatient unit, using the clipboard list to ascertain what food had been ordered by the patients in each room. She knocked on each door, even those that were open. She went in and asked the patient if he or she was '*ready for supper*' and '*are you sitting comfortably?*'. She asked if they would like '*your tray*' indicating the beanbag tray which was hung on the wall. She left the trolley in the corridor and walked back and forth to take things into and out of patient rooms.

The first room on the list was occupied by the patient who was PEG fed. There was a carton of Fortisip²² on her meal tray. Katy decided to ask a nurse about it and knocked on the door of the nurses' office. A nurse opened the door and Katy explained what she wanted. The nurse took the carton and said that she would 'do it'.

At the next patient after the PEG-fed patient, she gave me the plate of sandwiches and asked me to give it to the patient and told me to take the cling film off. I did this and put the plate and paper napkin which was also on the tray on the patient's over-bed table. She asked the patient and her visitor if they would like tea or coffee and noted the order on the clipboard.

The next patient had ordered soup. There was an empty bowl on the tray on the trolley, and I asked whether we needed to go back for the soup. Katy said, 'It's there!', pointing to a flask attached to the trolley with Velcro. I held the bowl for her while she filled it. She took it from me and took the bowl in to the patient. I took the flask and fastened it back to the trolley. Katy asked if the patient or her visitor would like tea or coffee and noted the order down.

One patient was sleeping. Katy called her name. She didn't respond. Katy went round to the other side of her bed (the near side was taken up with the over-bed trolley) and gently shook her shoulder, calling the patient's name, but she did not stir. The patient had not ordered supper, but Katy told me she would have asked her if she wanted tea or coffee.

The next patient was sitting in the relatives' area watching TV with a visitor. Katy asked her if she would like to eat 'here'. The patient said that she would, and Katy gave her the sandwiches she had ordered.

Katy then checked the supplies in the relatives' kitchen area – tea, coffee, milk in the fridge, and clean cups and mugs in the cupboard. There was some dirty crockery in the sink which we put on a tray on the trolley.

The next patient was lying in bed. There were two relatives in the room. The patient had not ordered any supper. Katy asked if there was anything she would like, suggested melon. The patient indicated that she would like this and Katy said that she would check with the kitchen if

²² Nutritional drink which could be used with PEG apparatus

they had any. She asked the relatives if they would like tea or coffee. She noted the orders on the clipboard.

The next patient was having cheese on toast – she was sitting up in bed. Katy knocked on the door, went in, asked her if she was ready for supper and ‘are you sitting comfortably?’. The patient said that she was. Katy gave her the plate of cheese on toast. ‘Enjoy’, she told the patient, and left the room.

We called into the patient who had been sleeping and was now awake. Katy asked if she would like tea or coffee. Katy noted her order.

We took the trolley back to the kitchen stopping to check tea and coffee supplies in the patient lounge. Katy took the coffee jar which was nearly empty and put it on the trolley. Back in the kitchen we changed back into the blue aprons and went into the store to look for coffee to refill the jar.

Katy asked Mandy for melon and also made the teas and coffees ordered by the patients. She loaded these onto another trolley, as well as some drinking straws from a jar on top of the water boiler. The cook gave her the dish of melon and the desserts which had been ordered (two sorbets). We headed back out into the main corridor. Katy called in to all the patients, dropping off teas and coffees where ordered and asking if they would like their water jugs to be refilled. The woman who had been asleep was asleep again, so Katy put her drink (tea in a beaker with a straw through the spout) on her over-bed trolley without waking her. She took water jugs from the rooms if patients asked for them to be refilled and put them on the trolley. We worked our way round. The woman eating her sandwiches in the relatives’ area asked her if she could keep the last one ‘for later’. Katy said that she could. She asked the patient if she would like her dessert and if she would like her water jug refreshed.

Katy continued to call in to each patient’s room to collect used crockery and to note down on the clipboard list how much each patient had eaten. She then returned to the kitchen. She made a coffee for one of the relatives who had asked for one on the second round. She asked me to take it out which I did. When I returned Katy had changed her apron and was washing up. I changed my apron and helped put away the clean crockery. Katy loaded up the dirty crockery and ran the machine. We did a couple of loads like this. Then she fetched clean water jugs and lids, and filled

them up from the main kitchen sink tap. I put on the lids and we put them on the trolley. We changed our aprons and went back out to deliver the fresh water and collect dirty crockery.

At the room where the patient had wanted melon, Katy asked if she would like anything else. Katy suggested yoghurt, and the patient's relative asked what flavours there were. Katy said slowly and clearly, 'Apricot?' Pause. 'Strawberry?', at which the patient indicated that she would like strawberry (the patient had some communication difficulties). One patient had ordered the hot dessert – rice pudding – and Katy checked with her whether she still wanted it.

We went back to the kitchen and changed our aprons. Katy told the cook that the patient wanted her rice pudding and the cook heated it in a microwave. Katy went to the fridge and found a strawberry yoghurt. She put these on the trolley. We changed our aprons and headed out again with a trolley.

Katy delivered the yoghurt and rice pudding to the relevant patients and collected some more dirty crockery, noting how much patients had eaten. We went back into the kitchen, changed our aprons and finished the washing up. At the end of the shift we went back up the corridor to the Nurses' Office. Katy knocked on the door and a nurse answered. We went in and she showed me the patient folders. She took each one off the shelf and opened it at the 'food and drink' tab near the beginning. She explained that if she didn't know how much the patient had eaten because she had not yet collected the dirty crockery the nurses would complete it later.

6.3 Hospitality and the production of 'living'

As I discussed in relation to the day hospice volunteers in Chapter 5, a key part of hospitality is that it defines the relationship between the actors involved in terms of 'host' and 'guest'. In the first part of this section I draw on Katy's vignette, together with examples from Daisy Hospice, to show how the volunteers acted as hosts ensuring the patients' – their guests' – comfort. In the second part I discuss how the volunteers helped to produce 'living' through encouraging eating and thus resisting dying.

6.3.1 Volunteer 'hosts'

Katy's vignette highlights how serving food to patients involved hospitality rituals. For example, Katy knocked on the patient's door – even when it was open – announced that she was serving supper, checked that the patient still wanted the meal, asked if he or she was 'comfortable',

arranged a lap tray, ensured the patient was sitting up (if they were in bed) and so on. Thus, the volunteers played the role of 'good host' (Telfer, 2000, p. 40) ensuring guests' comfort and safety (King, 1995). However, in contrast to their counterparts in the day hospice, inpatient unit volunteers did not develop social relationships with patients; they accessed patient rooms only to perform specific tasks and not specifically for social reasons, although if a patient were awake, the volunteers always said hello and sometimes had a brief chat, for example, about the weather.

As I showed in Katy's vignette, another aspect of her hospitality role concerned 'adapting' the menu to suit the patient as in the example of offering melon. I also saw this at Daisy Hospice. Here a different system operated. A cook brought the food to the inpatient unit kitchen on a heated trolley from which he or she served it. From my fieldnotes on a shift with volunteer Cathy:

Cathy went to pick up one of the trays with a lunch on it that the cook had dished up. She checked which patient it was for, and then explained [to the cook] that another patient needed to have his carrots mashed, 'not like mashed potato, but just crushed', she said. She left the kitchen to take the meal to the patient. Cathy came back and took another meal. The cook came back and started cutting up the carrots in the container on the heated trolley. Cathy returned and asked again about the carrots, adding that the patient also needed the sausages to be cut up as well. The cook did this while Cathy took another meal out. She came back and said that she thought the cut-up sausages looked good. The cook added the carrots he had cut up and some mashed potato.

This fieldnote shows how Cathy 'advised' the cook, in this instance reminding him about food which needed to be cut up or mashed. On other occasions volunteers suggested adjusting portion sizes (usually to reduce them) to suit a patient's appetite. This attention to detail is in keeping with hospitality as an expression of care (King, 1995). Importantly, by taking the trouble to ensure that the food was served to patients in a way that increased the likelihood of them being able to eat it, the patients could continue 'living'. Such care was also evident in how food was presented as illustrated in my fieldnotes of a shift with volunteer Nancy:

Nancy started making toast for a patient. She got a tray, put a doily on it and so on.²³ She told me that Gaynor [the housekeeper] liked food to be presented to patients attractively. I asked what she

²³ By this time in my fieldwork I had followed many other shifts so knew this routine well.

meant, and she said she'd show me, carrying on making the toast until she ended up with four triangles of buttered toast and marmalade with the crusts cut off (she said that she thought the crusts were useful to avoid getting sticky fingers but cut them off as that's what Gaynor likes) arranged on a plate, with a paper napkin tucked alongside.

I noticed that at both hospices the volunteers did not 'plate up' food intended for the 'main' meals of lunch and supper; this was always done by the cooks. The volunteers served only soup and, at Daisy Hospice, when the volunteers arrived early enough (see section 6.4.2), breakfast cereal and toast, as well as pre-made items stored in the inpatient unit kitchen such as jelly, ice cream and tinned fruit. Drawing on Douglas (1975), 'proper' meals were therefore served by the cooks while the volunteers served 'snack' items. This contrasts with the arrangement in the day hospice where the volunteers served the main meal food in front of the patients (Chapter 5). In Chapter 5 I suggested that this practice was part of the production of 'home' in the day hospice, given the symbolic status of 'proper' meals in producing 'living'. In the inpatient unit, however, where patients are closer to death, serving the 'proper' food was carried out by 'professional' staff – the cooks. This begins to suggest the importance of the life-death boundary in constructing the volunteer role. The closer the patients are to death, the more paid 'professional' staff are involved.

The concept of the 'last meal' arose only once during the time I observed. On a supper shift at Daisy Hospice volunteer Nigel served ice cream for a patient. This was the first shift I had undertaken with Nigel who, without prompting, gave me a running commentary throughout. I wrote in my fieldnotes:

Later, he served ice cream for a patient. He had asked her how much she wanted and she said a medium portion. He told me about his 'way' of doing it. He took a mug, filled it with hot water from the water boiler, and used it to warm up the ice cream scoop. He then put three scoops [of ice cream] into a bowl. He took great care and told me that 'This could be a patient's last meal, so it's important that it looks nice'.

On another occasion, he told me that he thought the hospice should serve wafers with ice cream 'To make it look good'.

This section has shown how volunteers as hosts adapted and served meals, using their initiative to help patients to 'eat' and thus to continue 'living'. As volunteer Gaye put it when I asked if she

was busy: 'Well we are [since most of the IPU beds were full] and we aren't; lots [of the patients] aren't taking part [by eating], if you know what I mean'. Helping patients to 'take part' also involved actively encouraging them to eat. This is the topic of the next section.

6.3.2 Encouraging eating, 'resisting' dying

As seen in Katy's vignette above patients ate relatively little. On that shift no patients had ordered the 'main' supper dish and two had not ordered anything. Katy tried to encourage one patient to eat something by offering melon. I noticed similar patterns on other shifts at both hospices. From my fieldnotes of a breakfast shift at Daisy Hospice with volunteer Deidre:

Where patients were eating – that is, not those who were 'NBM' ²⁴ – Deidre asked if they would like to order their lunch. She read out the menu to them(...) She tried to encourage the patients to eat, saying things like, 'Give it a go'. With one patient, who didn't really want to eat, she suggested everything she could think of – egg, fish – in a bid to encourage the patient to eat. Another patient explained that he had a stent fitted so didn't think he could manage the items on the menu. Deidre suggested he could have some fish. He seemed quite keen on this, so she said she would ask the cooks. Later she said to me that they [the cooks] will complain and say that fish comes in on Thursdays but too late for lunch, but that they always have some in the freezer.

Patients tended to eat smaller portions as their illness became more advanced. These patients were less likely to eat the 'main' meal, instead asking for just one or two items, such as mashed potato and gravy, or in one instance, just sweetcorn. Thus they 'resisted' the imposition of the 'traditional' food model of three meals a day. Eating 'well' was regarded by volunteers and staff as important, and the volunteers would praise the patients if they had eaten their meal. For example, when collecting used crockery, volunteer Rhona commented to a patient that she had 'done very well with your food today. It will give you a little bit of strength'. One of the ward hostesses at Flora House explained to me how upset she had been by a patient who had died 'while seeming well', which she defined by the fact that he had eaten 'well' the day before. Komaromy (2005) has argued that not eating (in the context of a nursing home) is interpreted as a marker of dying. Three meals a day, and in particular the three-course dinner, is an idealised form of eating compared with other eating 'events' such as snacks, which are deemed less healthy and

²⁴ Nil By Mouth – 'NBM' was noted against patient names on the kitchen whiteboards.

even morally deviant (Warde & Yates, 2017). However, as patients became sicker, it seemed that nutrition became less important than just eating ‘something’. Jelly and ice cream – never on the menu but always available – were offered to patients who exhausted other food options. Very many times I heard both volunteers and staff say when offering this dish, ‘*That slides down*’, ‘*It slips down*’ or ‘*It slips down easily*’, as if the difficulty of eating was the ‘problem’ rather than the fact that lack of appetite and/or inability to eat were linked to the dying process.

Seale (1998a) suggests (following Douglas’ ideas about what constitutes a ‘proper’ meal (1975)) that closeness to death can be marked by a shift from solid food to liquids, from meat to vegetables. The consistency of jelly and ice cream categorises the dish as midway on the solid-liquid continuum, and thus could be seen as symbolic of patients’ journey towards death. Food is also a marker of care (Seale, 1998a), and the practice of withdrawing food and drink from patients in the last days of life is seen as cruel by people not familiar with the needs of people with advanced disease, because of the symbolic nature of food and drink as an integral part of the nurturing relationship (McInerney, 1992). Sometimes when volunteers collected used crockery from patient rooms, they left uneaten food (usually cake), telling the patient that they ‘could nibble on it later’ (or similar). Thus, food and eating became ritualistic rather than instrumental, so that ‘living’ could continue to be performed by those who were dying.

Food also became medicalised as seen in Katy’s vignette about the patient who used a PEG device. Other patients required liquids to be thickened and in the inpatient unit the nursing staff always took over from the volunteers in the instances I observed. As the volunteer role was concerned only with producing ‘living’, as can be seen in Katy’s vignette, ‘medicalised’ food, such as PEG feeds, marked the boundary of the volunteer role in the inpatient unit. Food practice also became increasingly ‘technologised’ as patients became more ‘poorly’ (this ‘folksy’ term was used by staff to refer to patients at advanced stages of illness). Not only was this change marked by a shift to less solid food, but also by the use of various food ‘technologies’ to help patients eat and drink (and thus carry on ‘living’). These included the use of beakers for drinks, ‘sticky’ mats to stop plates sliding around on meal trays and cutlery with easy-to-grip handles.

The quantity of food patients ate was used by staff as a proxy for health status. As described in the vignette of a shift with Katy, volunteers were required to record how much patients had eaten. At Flora House the volunteers wrote directly into a section of the patient notes (kept in the nurses’ office), but at Daisy Hospice they completed a pre-printed form marking the percentage of each dish the patients had eaten. They did this in the inpatient unit kitchen so that they did not

have to enter 'forbidden' spaces. On several occasions they remarked to me while doing this that they thought it meaningless as there was no requirement to note the original size of the meal. One of the healthcare assistants took the form and entered the information into the patient records which were held electronically. I asked one of the nurses what it was used for and she told me that it gave a general indication of a patient's overall 'health' – the more they were eating the better. Thus, food was used by the hospice as a marker of 'living' and, I argue, 'eating' and 'not eating' were proxies for 'living' and 'dying'.

As patients ate less, volunteer contact with them reduced considerably. At Daisy Hospice one breakfast volunteer told her colleague: 'I didn't go into 'xxx' room as she isn't eating'. However, I noticed that they usually changed the jug of drinking water even when patients were not drinking ('NBM' on the kitchen whiteboard, described below in section 6.4.1). When I asked the volunteers about this, they were always vague as to why they changed the water for 'NBM' patients, saying *'That's what we do'*. However, water is symbolic of life (Wagner, 2013) and so this practice could be interpreted as a reluctance to let the patient slip out of the category of 'living'. Lawton (2000) argues that before physical death occurs there is a 'social' death when social contact with the patient is considerably reduced. Since food practices were the key medium through which volunteers communicated with patients and gave them legitimacy in their care, my data show how these practices positioned volunteers within 'living' and away from the living-dying boundary. Below, I explore this boundary further by examining the patient rooms and how volunteers accessed these, but first I examine other boundaries which I argue helped to construct the volunteer role.

6.4 Isolation through boundaries

This section focuses on four boundaries which can be seen in the shift with Katy above and which show how the inpatient volunteer role was isolated from that of staff: clinical boundaries illustrated by access to patient information; temporal boundaries formed from the institutionally imposed shift patterns; spatial boundaries exemplified by spaces used by volunteers for their breaks; and organisational boundaries.

6.4.1 Clinical boundaries

As seen from the vignette Katy's access to patient information was limited to what was written on the kitchen whiteboard. There was a similar whiteboard in the inpatient unit kitchen at Daisy

Hospice. The main purpose of the information on both boards was to communicate patients' dietary needs to staff and volunteers involved with serving meals.

At Flora House the board hung on the wall overlooking the dividing counter in the kitchen, so could be seen from both sides. At Daisy Hospice there was a whiteboard in the main hospice kitchen (not used by volunteers) and another in the shared kitchen area in the inpatient unit. These whiteboards listed the patient rooms – using the room numbers at Flora House and names at Daisy Hospice (see Chapter 4). The 'unit' of care was therefore the room rather than the patient, and I overheard staff refer to room number or name rather than patient name within staff-only 'back-stage' spaces. The organisation of work around patients objectified as rooms is seen in other care settings, such as care homes (Wolkowitz, 2011) and seemed counter to the person-centred approach on which palliative care is based (Seale, 1998a).

The first name of the patient using the room was written in the first column, with other columns for information connected with eating and drinking including, dietary needs, such as 'lactose intolerant', 'low salt' or 'diabetic'; special equipment required for eating or drinking, such as a beaker for drinking; and likes and dislikes, such as 'prefers white bread' or 'has own tea bags'. Medical terms, other than common ones such as diabetic, were also used but 'coded' with acronyms, such as 'NBM' (nil by mouth) or 'PEG'. A red dot was placed next to the names of patients who were deemed 'end of life', that is, 'actively' dying. These patients did not eat or drink. In this way the reality that dying was happening was thus sequestered and anyone seeing the whiteboards who was not part of the performance of hospitality would not know that it was taking place.

Volunteers arriving for their shift brought themselves up to speed using the kitchen whiteboards. At Daisy Hospice, where some shifts overlapped, the 'outgoing' volunteers ran through the list of patients with the incoming volunteers mentioning additional issues, such as not being able to serve a meal because a patient was sleeping, or the need to cut up or mash food. Sometimes Gaynor, the housekeeper, passed on the information to the breakfast shift volunteers. Some volunteers made notes, referring to these during their shift, for example, to check which patients 'were eating' and which used a beaker. Babs and Fran on the morning shift at Flora House used a small notebook which Babs brought with her. At Daisy Hospice some of the volunteers I followed transferred information from the whiteboard to a special form which they then used as a memory aid, keeping it in the pocket of their tabard apron. Spare copies of the form were kept in a folder kept on top of the fridge-freezer in the IPU kitchen.

As in the day hospice volunteers did not know patient surnames. This could lead to difficulties. While I was observing volunteer Deidre at Daisy Hospice, a nurse came into the IPU kitchen and told her that 'Mr 'X's' relatives' had arrived and asked her to offer them a cup of tea (Mr X had recently died). Deidre asked what the patient's first name had been as patient's surnames were not included on the kitchen whiteboard. Another volunteer at Daisy Hospice told me about an occasion when a nurse had told the volunteers to address patient relatives as 'Mr or Mrs xyz', but that they had pointed out that they did not know the patient's surnames so could not do this.

Volunteers were also not told patient diagnoses. One of the volunteers at Daisy Hospice told me, *'We aren't told the diagnoses, unless it's a brain tumour which affects their behaviour. You just have to take the patients as they are'*. One of the afternoon volunteers at Daisy Hospice had been a senior nurse before retirement. She told me that she would like a 'proper report' so that she knew more about the patients and, in particular, their families. *'I'm not being nose'*, she said, *'I can work out where the cancer is'* but I want to know a bit more about them. She said that there had been a *'very good nurse years ago'* who used to tell her this information, but this no longer happened.

Less confidential patient information was given to the inpatient unit volunteers compared with the day hospice volunteers. As I discussed in Chapter 5 controlling access to patient information has been shown to be a professionalisation project by staff (Overgaard, 2015). The volunteers were therefore being positioned in a subordinate role with clear boundaries. As the information was imparted via whiteboards rather than in person, the effect was to distance the volunteers from clinical staff working in the inpatient units. Volunteers, particularly at Flora House, were also isolated from other volunteers as I show in the next section.

6.4.2 Temporal boundaries

In Chapter 3 I gave an overview of the inpatient unit volunteer shift patterns (see section 3.4.4). Here I expand on this to show the temporal boundaries of the volunteer role and how these isolated volunteers from other volunteers, particularly at Flora House although, as I will show, to some extent volunteers 'resisted' these boundaries.

At Flora House volunteer shifts started thirty minutes before the next 'food event' was due to be served and were known as 'morning' (9.30 am to 11.30 am), 'lunch' (12 noon to 2 pm), 'afternoon' (2.30 pm to 4.30 pm) and 'supper' (5 pm to 7 pm). At weekends there was no supper

shift since there was no evening shift for the cooks. I was struck by how volunteers did not meet volunteers on other shifts. For example, in the time I followed Katy and other supper volunteers, none met any afternoon volunteers. It was different at Daisy Hospice where shifts were contiguous or overlapped: 'breakfast' (9.30 am to 1.00 pm), 'afternoon' (12.30 pm to 4 pm) and 'supper' (4 pm to 7 pm). Gaynor (who also organised the volunteer rotas – see section 6.4.4), told me that the overlap between the breakfast and afternoon shifts had been suggested by the volunteers themselves in order to serve lunch more efficiently. Thus, the volunteers had 'resisted' the institutionally imposed temporal boundaries. I noticed that they also did this 'unofficially'. Mandy, who I followed on a weekend breakfast shift, told me that she had arranged with her colleague to handover at 2 pm, rather than 12.30 pm, as '*I don't have anything else to do*'. The afternoon volunteer then covered the vacant supper shift. Thus, volunteers adjusted shift times both for reasons of personal convenience and because they wanted to be as useful to the hospice as possible. Volunteers at Daisy Hospice did likewise, including Fran – a morning volunteer at Flora House – who told me she arrived early as she came to the hospice after taking her children to school. Her partner, Babs, said she preferred early starts as they had been her life-long pattern. They told me that if they ran out of work before the end of the official shift time, they left early, but that they sometimes stayed up to an hour longer if there was more to do. Afternoon volunteers, Rita and Liz, arrived at 2 pm rather than 2.30 pm. They told me that if they did not start at this time, they would not be far enough ahead with the work in the laundry to be able to serve tea 'on time' at 3 pm.

'Keeping busy' was important to the volunteers, and two 'morning' volunteers at Daisy Hospice told me separately that they arrived early – at 8 am or earlier – because they felt it was most helpful to staff if they arrived in time to serve breakfast, which was otherwise served by the Housekeeper or healthcare assistants. On one occasion when I followed Nancy who arrived at 8 am on Sundays, one of the staff nurses said to her, '*You're a diamond, coming in so early*'. The volunteers also looked out for each other in this regard. On an afternoon shift with Rhona, I asked if I could help unload the dishwasher. She told me she would leave it for the supper volunteer who otherwise would not have much to do. One of the ward hostesses at Flora House also told me, '*The volunteers come a long way and don't want to do nothing when they get here*'.

'Keeping busy' may have been a method of legitimising the volunteers' role with staff. It draws on a discursive strategy of volunteering as 'helping out'. I discuss this again in Chapter 7 in relation to the care assistant volunteers.

Having seen how the volunteer role was contained by institutionally imposed temporal boundaries and how volunteers 'renegotiated' these, I now turn to consider how the volunteers lacked a 'place of abode' in the hospice.

6.4.3 Spatial boundaries

In the vignette above Katy used the kitchen space as a 'base', collecting and preparing the items she needed to perform her role. Therefore, in Goffmanesque terms the kitchen was a 'back-stage' space. I noted that she was 'comfortable' taking her break in this area, chatting easily with the cook on duty. However, there were no other staff present, other than a few office staff returning used crockery. I noticed that volunteers on other shifts were less 'at home' in this space. Lunch volunteer Dot and afternoon volunteers Rita and Liz also took their breaks there. However, the space was also used by staff at these times and the cooks were all still on duty in the food-preparation area. Although these volunteers tried to join in the staff conversations, these efforts seemed to me awkward and stilted. Babs and Fran, the 'morning' volunteers, seemed particularly uncomfortable about taking a break in the kitchen area. They started their shift by checking the whiteboard in the kitchen (described in section 6.4.1), then went to the laundry to '*get things going*' as they put it. While in the kitchen they made themselves a drink, but drank it quickly standing up rather than sitting at the table. They sometimes took a second break towards the end of the shift using the patient lounge area which was usually unoccupied. On one shift Fran was alone when Babs was on holiday. From my fieldnotes:

She said that she was thirsty but didn't feel right having cups of tea, like Babs did. She told me that if she was on her own she just had some water. She referred to the nurses who had been on their break sitting round the table in the staff dining area, saying that she didn't feel right having a drink in front of them. 'We're only here for 2 hours', she said..... Later, she said again that she was thirsty. By this time she had delivered all the water jugs and done tea and coffee orders, and was waiting for the washing machines and tumble dryers to finish. She said, 'Let's go to the other area' [to have a drink], by which she meant the relatives' area rather than in the kitchen, as she was a bit embarrassed by having a drink in front of the nurses.

At Daisy Hospice volunteers took breaks when there was a lull in their workload. Since there was nowhere to sit in the IPU kitchen, they either drank a cup of tea or coffee standing up in this area or went to another part of the hospice, such as the courtyard garden, a staff meeting room or the day hospice room, checking first that the spaces were not in use.

Volunteers therefore seemed to find it hard to find a 'place of abode' (Lefebvre, 1974/1991, p. 193) and to 'belong' in the same way as staff, groups of whom took their breaks in the staff room at Daisy Hospice, or kitchen or one of the lounge areas at Flora House. Thus, volunteers used hospice spaces differently to other actor groups, bound by spatial boundaries beyond those created by locked doors and other barriers discussed in Chapter 4.

6.4.4 Organisational boundaries

During my shifts with Katy and the other supper volunteers at Flora House, their main staff contact was with whichever cook was on duty. As can be seen in the vignette they had little contact with clinical staff. The cooks provided relatively little direction except for setting the pace of the shift since the volunteers could not take each course to the patients until it was ready.

The morning and afternoon volunteers at Flora House, who also helped in the hospice laundry, received little supervision from staff during the course of their shifts. They had most contact with the two housekeepers, whose role was concerned with janitorial tasks, such as cleaning, laundry tasks in the absence of volunteers, and keeping stock and linen stores in order. The volunteers had a friendly relationship with them, engaging in good-natured banter when they met in the laundry, but the housekeepers left the volunteers to work alone. These volunteers had little contact with other staff, other than the ward hostesses and Chaplain. They passed the chaplain's office several times during a shift and he sometimes joined them when they took a break in the relatives' lounge area.

The two ward hostesses (one of whom was on duty at any one time) served breakfast to patients, took lunch orders and undertook 'housekeeper' duties such as setting up patient rooms for new patients. As with the housekeepers they did not directly supervise the volunteers. The exception was Dot, the lunch volunteer I followed, who at the time I observed had no partner. Because of this the ward hostess on duty helped to serve lunch. She went through the list of lunch orders with Dot at the beginning of the shift, pointing out patients who were 'not eating', and once asking her to check that a patient who had ordered a fried egg still wanted it. Dot always 'demurred' to her. On one occasion, having been asked to do something she said, '*No, that's fine – you're in charge!*'. On two occasions I followed Dot when the ward hostess was too busy to join her, so Dot served lunch without her – another member of staff did not step in.

I was puzzled by the 'light touch' or lack of supervision of the inpatient unit volunteers, particularly of the supper volunteers by the cooks since the volunteers worked so closely with

these staff. I noted later from the hospice organisation chart that all the inpatient unit volunteers reported to the senior nurse on duty. However, my data showed they did not have any contact with this person. Therefore, I asked several volunteers who this person was but none could tell me.

At Daisy Hospice aspects of the housekeeper and ward hostess roles I had seen at Flora House were undertaken by a single member of staff, Gaynor, who had specific supervisory duties in relation to the volunteers, including arranging a twice-yearly meeting, training and compiling volunteer rotas. (These tasks were done by the Volunteer Coordinator at Flora House.) Volunteers whose shifts overlapped with Gaynor's, who worked from 7.30 am until 3 pm, had a great deal of contact with her and they appreciated how she liaised with staff on their behalf. Volunteer Deidre told me that Gaynor *'looked out for the volunteers'*. I asked what she meant and she said that the housekeeper *'saw things from the volunteers' point of view'*. For example, if a new routine – such as the recent introduction of a form to record patient food intake – was proposed by the clinical staff, Gaynor put forward the volunteer point of view. Volunteers on weekend shifts (when Gaynor did not work) told me that they missed having someone who could liaise with staff on their behalf. I asked Deidre whether she reported to Gaynor, *'It's a bit muddled. I think the Nurse Manager is in overall charge, but Gaynor is our line manager'*, she said. However, as at Flora House, according to the hospice organisation charts, the inpatient unit volunteers reported to the nursing 'shift leader'. Again, my data showed that none had any contact with this person, and unless the Nurse Manager or her deputy was on duty, the volunteers I asked did not know who was in charge of the shift. In an extended conversation with the Nurse Manager, she told me that she used to manage Gaynor but this was now the role of the Support Services Manager as the role was hospice-wide rather than just related to the IPU.

At both hospices, in the absence of volunteers, the lowest ranked members of staff on duty in the inpatient units covered their roles. At Flora House the ward hostess did so when Dot was absent, and on a supper shift the healthcare assistants – the lowest rank on duty – covered for the volunteers. This fieldnote records what happened when volunteer Hattie had mobility difficulties on a supper shift when her partner was absent:

After the break we went back into the kitchen to finish some washing up. As Hattie has a mobility problem, the cook asked if she was OK to take the food to the patient rooms. Hattie said that maybe she wasn't. The cook said that she would ask one of the nurses to do it – it seemed no

problem to do this. She left the kitchen to go to the nurses' office. A short while later one of the healthcare assistants appeared – she didn't seem too keen – she took the first courses (soup) to the patient/visitors who had asked for them. Hattie and I continued washing up.

At Daisy Hospice I arrived to follow a breakfast volunteer at a weekend. The volunteer had not yet arrived and the senior healthcare assistant was in the kitchen organising two other healthcare assistants to serve the meal. Later I asked him about this and he told me that the healthcare assistants serve breakfast if both the housekeeper and volunteers are absent.

In this section I have shown that the volunteers had most contact with staff to whom they did not report and most of whom were low in the hospice hierarchy. As I discussed in Chapter 2, hospice clinical hierarchy is largely taken from the NHS, with healthcare assistants, ward housekeepers/hosts and domestic staff lower in status than doctors and nurses (for example, <http://www.uhs.nhs.uk/PatientsAndVisitors/Yourstayinhospital/Staffontheward.aspx> accessed 25 May 2018). In the absence of volunteers, the lower-grade staff covered the volunteers' tasks. In both hospices' organisation charts inpatient unit volunteers reported to the nurse in charge of each shift. However, none of the volunteers I followed knew who this person was and there was some confusion about lines of reporting. Volunteers performed their tasks with little supervision which suggests that they were not part of the work of the inpatient unit. However, the volunteers were appreciated by staff, as the comment I reported above showed. *'We can't do without them'*, a nurse told me. On one occasion when I arrived in the inpatient unit when Gaynor was absent and the volunteers had not yet arrived, the Senior Healthcare Assistant who, with a colleague, was preparing patients' breakfasts, rather grumpily told me it was not his job to do this. Therefore, on one hand volunteers were being positioned low in the hierarchy, while on the other hand they were being treated as if they were not part of the hierarchy at all, as if they were invisible and so outside of organisational boundaries.

In this section I have discussed four boundaries which isolated the volunteer role from staff: clinical, temporal, spatial and organisational. These served to constrain the volunteer role keeping them outside the 'team' of staff in the inpatient units. However, as I argued in Chapter 2, following Froggatt (1997) the hospice is concerned with ensuring patients move through the liminal space between life and death so that the life-death boundary is 'safely' negotiated. I argue therefore that the boundaries I have discussed in this section helped to keep volunteers away from the period in a patient's 'journey' when he or she was moving, or had moved, from 'living' to death through the liminal phase of 'dying'. This albeit difficult-to-define territory belonged to the

'professional' staff. I term this boundary the living-dying boundary. Since it was physically sited in the patient rooms, which the volunteers accessed as part of their role, I now examine the volunteer role in these complex spaces in more detail.

6.5 Producing the living-dying boundary – focus on patient rooms

In Chapter 4 I began an exploration of the patient rooms showing how they were both front- and back-stage areas, sites of living, 'living', dying and death. I described how hospice ideology of 'hospice as home' was expressed through some aspects of the décor and furnishings of the patient rooms. In this section, I examine the volunteers' interaction with these spaces and how this further illustrates the bounded nature of the volunteer role. Twigg (2000) argues that the characterising features of 'home' are: privacy, the power to exclude and the embodiment of identity (p. 79). I am concerned here with the first two of these. The last I described in Chapter 4 in showing how the patients brought some of their personal belongings into the hospice (also Kellehear et al., 2009). First, I discuss the patient rooms as sites of hospitality.

6.5.1 Patient rooms as sites of hospitality

Privacy is essential to the notion of 'home', linked to which is the power to exclude (Twigg, 2000). In Chapter 4 I described how the doors to patient rooms were usually kept open except when care was being given. As seen in Katy's vignette, she knocked on the doors even when they were ajar, and I saw other volunteers doing the same even when patients had indicated – for example, by making eye contact – that they had seen the volunteer coming. I argued in Chapter 4 that the patient rooms were their 'places of abode' (Lefebvre, 1974/1991, p. 193). Therefore, the volunteers' knock can be interpreted as an acknowledgment of this and is akin to what a visitor to someone's home would do. The knock gave patients the chance to refuse entry, although I never saw this happen, and when the door was open, patients 'colluded' by not talking to the volunteer until they had knocked. The volunteers also knocked when the patient was unable to respond, when asleep, for example. As Twigg (2000) suggests the parts of a home into which visitors are invited become 'public' 'front-stage' spaces. Therefore, the volunteers' knock served the purpose of changing the status of a patient's room from private back-stage space to 'public' front-stage space. Once the room was 'opened' in this way, the volunteers did not knock to re-enter to complete a specific task. For example, when I followed Fran at Flora House, she knocked on a patient's door to attract attention and offered tea and coffee. On this occasion she was not serving from a trolley but was making each drink individually in the relatives' kitchen area at the

end of corridor #2 (I have not recorded the reason for this but, from following other volunteers, I suggest it was because there were relatively few patients at the time). She left the room to make the drink, returned *without* knocking, then asked the patient if he would like a biscuit. She left the room and returned with a biscuit on a plate. She knocked only on the first occasion – after that the room was ‘open’ to her as she was still performing the task: giving the patient tea and biscuits.

Patients’ doors could be closed for a number of reasons, most commonly because the patient was receiving care from clinical staff, but also because the patient and/or their visitors wanted privacy or because the patient had died. Both hospices operated a system of ‘warnings’ to alert others that the patient room had become ‘forbidden’ space, open only to those with the correct status. If the patient was receiving care shutters were closed over the window. At Flora House this was supplemented with a laminated paper ‘hand’ held in place with a magnet. The volunteers did not enter the rooms when the shutters were closed but moved on to the next patient. I noticed that clinical staff came and went freely through the door (as I will show in Chapter 7). If the door was shut but shutters were not closed, the volunteers looked through the window to ascertain whether it was appropriate for them to enter. For example, at Flora House I followed Rita serving tea during an afternoon shift. I wrote in my field notes:

Room 1 – door closed – Rita looked in through the window and knocked on the door – there were a couple of visitors – Rita went in and asked if they’d like tea.

Sometimes a member of staff was with a patient, but the door was open. If this was a doctor, the volunteers passed by. Several told me of their annoyance that doctors were in the patient rooms at lunchtimes which were supposedly ‘protected’ to allow patients to eat their meal uninterrupted. If the member of staff was of lower status than a doctor, they usually engaged with the volunteer. For example, on an afternoon shift at Daisy Hospice I followed Rhona while she was serving tea:

The rehabilitation assistant was with one patient. Rhona started to move on to the next patient rather than go into the room, but the rehabilitation assistant asked the patient if she would like some tea.

I argue that this shows the member of staff ‘colluding’ with the volunteer in her performance of hospitality. However, a further example shows the opposite and illustrated how patient rooms

could become 'sites for potential conflict as public meets private' (Howarth, 1996, p. 45).

Combining Lefebvre's ideas with Goffman's (see Chapter 4), the rooms became junction points where back stage and front stage collided. This example is from my fieldnotes from a breakfast shift with volunteer Betty at Daisy Hospice:

Two patients were sharing one of the twin rooms Betty had quite a lot of difficulty getting into the room for one reason or another – first, the door was closed because one of the patients was having personal care, then a doctor arrived as Betty was changing the water – the doctor didn't acknowledge either of us, blanking us out and carrying on towards the patient. Betty finished what she was doing – also replacing the water for the other patient in the room. There was quite a bit of awkward bumping into each other, saying 'sorry' – the doctor didn't want to wait for Betty to finish. Betty then went to the other patient in the room, who was the one who had been asleep so hadn't had breakfast. The doctor pulled the curtains round the bed of the first patient (who was in the bed nearest the door). I left Betty to go to the other patient and waited outside – it was getting a bit crowded in there.

This example shows a hierarchy of tasks in operation with those being undertaken by the staff giving personal care and the doctor's taking precedence, positioning the volunteer's tasks as of lesser importance. I revisit the issue of hierarchy below, and now consider the patient rooms as sites of death and dying.

6.5.2 Patient rooms as sites of death and dying

When a patient died, in addition to closing the shutters over the windows in the doors, staff put signs on the door. At Flora House two signs were used, 'Do not disturb' and 'Ask a nurse before entering'. At Daisy Hospice the equivalent sign read, 'Do not enter'. Although staff and volunteers knew what these signs indicated, they gave the appearance to 'outsiders' (patients and visitors) that a patient was receiving care. In this way death was sequestered and the performance of 'living' could continue in the rest of the inpatient unit. Two fieldnotes illustrate this, the first from a lunch shift at Flora House with volunteer Dot:

Dot and I set off back down [corridor #1] towards the kitchen. A relative came out of a patient's room just as Dot and I were passing – he was tearful and told us that he was xyz's brother and that xyz 'had passed' (he spoke to me – I wasn't wearing a plastic apron, but Dot was, so maybe he thought I was a member of staff?) – one of the nurses overheard and went back into the room

with him – she put up the ‘Do not enter sign’ and closed the shutters on the window in the door. Dot and I continued down the corridor – another nurse apologised to me ‘I’m sorry about that’, she said. We continued to the kitchen.

The second from a supper shift at Daisy Hospice with volunteer Erica:

Erica worked her way down the unit [taking refreshed water jugs]. We were coming out of one patient’s room, when a nurse came out of the next room. She said very softly, ‘Don’t go in there, the patient has just died’. She left the door very slightly open. Erica continued with her task.

These examples also show how volunteers colluded with staff to ensure that the performance of ‘living’ could continue. In Mary Douglas’s terms chaos was averted through the imposition of routines (Douglas, 1966/2002). In neither case did anyone ask Dot or Erica if they were upset by the death, and it was telling that the nurse apologised to me as if my day had been interrupted by this ‘out-of-place’ event.

After the patient death at Daisy hospice, Erica and I chatted in the inpatient unit kitchen. She indicated that she did find patient deaths upsetting and also described how sight of a corpse being moved was hidden from volunteers (I described how this was done at Flora House in Chapter 4):

Erica said to me that if I asked about the worst bits of the role (I had asked her this the last time I’d followed her), she would say ‘when people die’. I asked if many patients had died during the supper shift, and she said ‘a few’, ‘it’s when they move people who have died earlier [in the day]; they shut the door [to the kitchen] but you know what is going on’.

However, Erica’s view contrasted with Deidre’s also a volunteer at Daisy Hospice, when I asked her about what happened when patients died:

She mentioned that she had asked to say goodbye to a patient who has died [who she had got to know] – she said that when they move a body, they [the staff] close the door to the kitchen because they think the volunteers will be upset but she asked if she could say goodbye and give them [the dead patient] a wave. I asked how they [the staff] reacted to this, and she said they were OK.

Thus, Deidre is resisting the discourse that volunteers need to be kept away from death. I pick this up in Chapter 9.

In this section I have discussed the patient rooms in more detail to show how these complex spaces – ‘junction points’ in Lefebvrian (1991, p. 193) terms – were both sites of hospitality and sites of clinical care, of dying and of death. Volunteers entered the patient rooms to provide hospitality. In order to do this ‘safely’, their role was contained within boundaries, notably the living-dying boundary.

6.6 Summary

In this chapter I have shown how the role of the inpatient unit general volunteers was concerned with the production of ‘living’ through hospitality, notably food practices. I described how the hospice used meal structure to create and reinforce structure and order, as well as its ideology of ‘home’. However, eating and drinking were also used as proxies for ‘living’ and ‘dying’. As patients’ health deteriorated, they gradually ate and drank less, and volunteers had correspondingly less contact with them, and no contact after patients had died.

I discussed five boundaries which constructed the volunteer role: clinical, temporal, spatial, organisational and the life-death boundary. I showed how the first four of these kept volunteers separate from staff and suggested that this was part of keeping volunteers were kept away from the fifth, the life-death boundary. I proposed that this may be because death and dying was the province of the ‘professional’ staff.

The isolation of the inpatient unit volunteers contrasts with the volunteer role in the day hospice, where, although the role was distinct from that of staff, volunteers worked with staff in a team. The difference between the two settings was that, although death and dying intruded in the day hospice, it was not literally present in the same way as it was in the inpatient unit. Patients did not die in the day hospice rooms. Since one aim of the day hospice was to promote ‘living’, death and dying had no legitimacy there. Therefore, there was no need to keep volunteers away from the life-death boundary and, in fact, the volunteers helped to ‘patrol’ the boundary with staff.

In Chapter 5 I introduced the idea of volunteers as potentially ‘dangerous’ because they have no ‘contract’. In this chapter, I have shown how the role of those who are involved closer to the life-

death boundary is more closely bounded and controlled. Drawing on Douglas (1966/2002) I suggest that this isolation makes them 'matter out of place' (p. 203) within the frame of the medical model of care. The volunteers I have discussed in this and the previous chapter undertook tasks which were allocated specifically to a volunteer role. In the next chapter, however, I explore a group of volunteers whose roles involved them directly undertaking tasks usually reserved for 'professional' staff to show the operation of strategies to deal directly with 'matter out of place'.

Chapter 7. 'Professional' volunteers: 'matter out of place'

In the previous chapter I discussed the inpatient unit 'general' volunteers and how they were isolated from other actor groups, particularly the clinical staff. I suggested that this may be because their roles involved contact with patients who were dying, which seemed to be the preserve of *trained 'qualified'* staff. Therefore, within the medical model of care, the volunteers were isolated outside the professional boundary of care.

In this chapter I consider a group of volunteers who offered their professional skills, that is, skills requiring a professional qualification. They included complementary therapists in the day hospices (and, at Daisy Hospice, an art therapist, a chaplain and an 'exercise volunteer'²⁵) and care assistants in the inpatient units. Most of these volunteers crossed the boundary of care into the sequestered 'bodywork' role of the clinical staff. Twigg defines bodywork as 'working directly on the bodies of others' for a range of purposes including medical, as in surgery, and therapeutic, as in complementary therapy (2000, p. 137). Since the dying process can involve such deterioration that the body becomes 'unbounded' (Lawton, 2000), bodywork is vital to the hospice production of 'living' and, as my data in Chapter 6 showed, was undertaken behind closed doors.

However, within a clinical setting bodywork involves dealing directly with the body and its wastes (Twigg, 2000, p. 139) and, as such, can be seen as 'dirty' (Hughes, 1958, p. 52). Dirty work tends to be performed by those in lower status positions since the 'delegation of dirty work is ... part of the process of occupational mobility' (Hughes, 1958, p. 52). As Twigg (2000) has argued, the hierarchical organisation of the nursing profession means that as their status increases, nurses undertake less 'dirty work' such as dealing with bedpans and, in the highest grades, no bodywork at all. Therefore, it would follow that volunteers, who I have shown to be low in the hierarchy in the inpatient unit, would be welcomed into roles involving such dirty work.

²⁵ Her role was similar to that of a rehabilitation assistant.

However, as I will show in this chapter, the concepts of bodywork and dirty work did not help to explain everything that was going on. I noticed that care assistant volunteers in the inpatient unit did not seem to be welcomed by staff. These volunteers constantly (re-)negotiated their role and seemed to find it hard to 'fit in'. On the other hand, complementary therapists in the day hospice appeared to have no trouble undertaking their tasks alongside staff. Instead, I argue that as volunteers crossed the boundary into bodywork, they became 'matter out of place' (Douglas, 1966/2002, p. 2003) within the frame of the medical model.

As I discussed in Chapter 2, Douglas characterised 'matter out of place' (p. 203) as either anomalous or ambiguous. Anomalous matter is that which does not fit any category within a classificatory scheme. Douglas suggests that various strategies are used to 'deal' with 'matter out of place' which can otherwise become 'dangerous'. These strategies range from merely ignoring it to killing it. Douglas' (1966/2002) example is of a tribe which removed the 'social anomaly' of twins by killing one at birth (p. 49). I will show how the volunteer care assistants were treated as anomalies by staff, who used strategies such as excluding them from the staff team, downgrading them and even sending them home. On the other hand, ambiguous matter is that which could belong in either of two categories and is dealt with simply by allocating it to one group or the other. Douglas' example from her anthropological work is of a tribe who allocated babies with what they saw as birth defects to the category 'baby hippopotamus'. The 'problem' could then be dealt with by placing the new-born in a river with the other hippopotamuses. I will show how the volunteer complementary therapists were allocated to the group 'staff'.

To explain the strategies used by staff with regard to the professional volunteers, I also draw on ideas about 'boundary work' which I outlined in Chapter 2. This refers to discursive strategies used by professional groups to create and maintain their status (Gieryn, 1983). Van Bochove et al. (2018) refined the concept to explain how paid staff performed 'demarcation work' to mark out their professional territory, but 'welcoming work' when they allowed a specific volunteer to become involved with what was usually their work. I will also show how the volunteer complementary therapists also undertook 'boundary work' to protect their 'professional' status. I begin by discussing the care assistant volunteers.

7.1 Anomalies: inpatient unit care assistant volunteers

Both hospices involved volunteers as healthcare assistants, largely in the same role as paid healthcare assistants. At the time of my observations this was a relatively new volunteer role,

having been established for less than two years in both hospices. As I stated in Chapter 3 I followed three volunteers in this role, one at Flora House and two at Daisy Hospice. All were women in their early or mid-60s and retired. At Flora House Eli had previously worked as a healthcare assistant at the hospice and returned as a volunteer covering one half-shift a week. At Daisy Hospice Lisa and Lucy, a former theatre nurse and community nurse respectively, also offered one morning a week (on different days).

The role focused on tasks involved in helping patients with personal care, including washing and dressing. As I stated in Chapter 3 I could not follow the volunteers while they were undertaking personal care for patients, but talked to them after they finished each job. The role differed from those of the volunteers discussed so far in this thesis in that it involved undertaking the same tasks as paid staff, often partnering paid staff. In the following three sections I describe the strategies employed by staff which reveal how they treated the volunteers as anomalies: excluding them from the staff team, 'downgrading' them, and sending them home early. In a fourth section I discuss these volunteers from the viewpoint of hospice management.

7.2 Excluding them from the team

At Flora House Eli attended the nursing team handover, while at Daisy Hospice Lisa and Lucy did not. This section discusses the consequences of this in three parts: handover, acquiring patient information and finding tasks to do.

7.2.1 Handover

Handover is a key part of establishing the nursing team (Holland, 1993; Payne et al, 2000; Strange, 1996). It forms an important ritual in nursing culture (Holland, 1993), and helps to build group cohesion (Strange, 1996) and professional identity (Payne et al., 2000). In addition, for nurses caring for dying patients, it provides emotional support (Hopkinson, 2002). I argue that not attending therefore meant that for Lisa and Lucy being part of the nursing team was more difficult than for Eli.

At Flora House Eli attended the handover between the night and morning nursing shifts.²⁶

However, she told me that she had initially not been welcomed at 'report' even though she was a former employee. I asked the volunteer manager about this. She told me that volunteers did not attend handover as the clinical staff thought volunteers could not be trusted with patient confidentiality and were therefore not happy about Eli attending:

.... some staff are not happy about her sitting in on handovers because of patient confidentiality – 'they [volunteers] can't be in uniform' – Eli has not always had an easy time – although certain staff have left so she is now more accepted. There has been a cultural shift, and small steps to more inclusivity, but they made her jump through hoops, but she's persevered.

Some staff had therefore seemed to view Eli as untrustworthy since she had become a volunteer, even though she was involved in largely the same role when employed by the hospice. Since it is reasonable to suppose she had not changed, it suggests that it is the construction of 'volunteer' that had altered their view of her. Ganesh and McAllum (2012), supporting van Bochove et al. (2018), discuss how 'professional' and 'volunteer' seem to be held in tension so that volunteers are not seen as professional. I return to this issue in Chapter 9, since it is relevant to all the volunteer roles.

Lisa and Lucy arrived at Daisy Hospice at 9 am and 8.30 am respectively (Lisa stayed late to take the hospice order for controlled²⁷ drugs to a hospital near her home at the end of her shift). By this time the paid healthcare assistants had paired up and were working their way round the patients, having attended handover at 7 am. I did not ask Lisa or Lucy why they did not attend handover, but I questioned the Nurse Manager about this and she seemed surprised that they should attend. I discuss my conversation with the Nurse Manager further below (section 7.5). The result of not attending handover was that Lisa and Lucy were not 'visible' in the nursing team and so had to 'negotiate' to find tasks to do. However, their first task on arrival was to access patient information which, as the next section shows, could be a struggle.

²⁶ I did not attend since I usually arrived in the hospice after they had finished.

²⁷ Some prescription drugs are controlled by legislation designed to prevent their misuse. The legislation covers how the drugs are stored, prescribed and disposed of (NHS website: <https://www.nhs.uk/common-health-questions/medicines/what-is-a-controlled-medicine-drug/> accessed 21/12/18).

7.2.2 Acquiring patient information

When I first met Lisa:

She said that she liked to go through the list of patients with one of the nurses at the beginning of her shift but that this didn't always happen, and that she also liked a copy of the written list [of patients – each member of staff had a copy of this. It was updated and reprinted each morning] but didn't always get this.

Lisa and Lucy therefore started their shifts by checking the whiteboard in the nurses' station. (I described this in Chapter 4 section 4.5.5). Sometimes a nurse saw them in the nurses' station and went through the list of patients with them. Lisa told me that if this did not happen, she checked each patient room to find out how many patients there were and how 'sick' they were, as sicker patients tended to need more help with personal care:

Lisa then walked up the length of the IPU looking in all the rooms – she said hello to the patients who were awake – Bella [senior nurse with responsibility for line-management of all other nurses apart from the Nurse Manager] appeared and took her round each patient again, introducing her. Bella told her a bit about some of the patients – in a couple of the rooms, she pulled out a file and explained that this was the patient's care plan..... She gave Lisa some medical information about each patient – she said about one that she was 'in for symptom control: nausea and vomiting'. At the end Bella asked if she would like a handover sheet, and Lisa said she would. Bella went into the nurses' station and printed one out from a computer. After Bella had gone, Lisa said to me, 'That's the best I've ever had' (i.e. handover – I wondered if it was for my benefit).

On one shift, when Lisa had been unable to find anyone to give her a handover, she asked Gaye (a general volunteer) to go through the patient list on the IPU kitchen whiteboard, although Gaye could give her only a general idea of a patient's condition based on whether they were 'eating' or not.

Both Lisa and Lucy told me that they found the handover sheet useful as it contained basic patient details such as diagnosis and age, and helped them to keep track of which patients had been 'done'. Sometimes the nurse doing the 'handover' offered a copy as in the example above. Sometimes they asked for one. For example, on another shift Lucy had not found anyone to give her a handover, but saw the physiotherapist photocopying one for herself and asked her to copy one for her. In one instance Lisa helped herself to some spare copies which were attached by a

bulldog clip to the wall near the whiteboard in the nurses' station. On another shift Lisa asked the ward clerk to print one out for her.

This section has shown how not attending handover meant that accessing patient information was difficult for Lisa and Lucy. Not attending the meetings also had implications for finding work for the rest of the shift. Eli told me that she usually '*teamed up*' (as she put it) with the healthcare assistant she had worked with for several years. She emphasised to me the importance of having a partner, and that without one it was difficult to fit into the flow of work. Without a partner, Lisa and Lucy found it difficult to find sufficient tasks to occupy their time.

7.2.3 Finding tasks to do – joining a game that's already started

Since patients were able to wake up in their own time and decide when they wanted to wash or get up, the healthcare assistants discussed among themselves to whom they should offer a wash next. At Flora House I saw Eli and her partner do this on several occasions. Staff therefore did not move from one room to the next sequentially, so the only way Lisa and Lucy could assess which patients may still require help was to ask either the patients or staff.

Sometimes Lisa or Lucy found a pair of healthcare assistants easily, asked which patients had 'been done' and then attended to a patient who still needed help. Sometimes, if they could not find any staff, they asked the patients if there was anything they needed or would like help with. The following fieldnote from a shift with Lisa shows how many times she had to ask for work, and how she found it by asking patients directly. It begins with her undertaking a task as a 'favour' to the hospice:

On another shift, I arrived to find that Lisa had not yet arrived. The Ward Clerk told me that she had rung Lisa to ask her to pick up some medication from a hospital near where Lisa lived. I waited for her in the IPU sitting area. She arrived carrying the medication and went in search of a nurse to ask what to do with it. She found one in the treatment room and knocked on the door. She asked what she should do next. The nurse said that she must be thirsty and should get a drink. She did so, drinking standing up in the IPU kitchen. She then went in search of someone to ask for a task. She eventually found two nurses in one of the patient rooms, but they had nothing for her to do. She then went round each patient asking if they would like help with a wash. After asking a few, one asked for a bath, which she helped him with. This took quite a while (I waited in the sitting area). When she had finished and had cleaned the bath, she searched for someone to ask for her next task, and found two nurses in another patient's room, but they did not have anything for her

to do. She went round the rooms again, asking the patients if they wanted anything. Two asked for a cup of tea, which she made and took back to them.

I was struck both by how many staff members Lisa asked before she found something to do, as well as by how the first nurse she spoke to avoided giving her a task by suggesting she should take a break, even though she had just arrived. I noted that Lisa took advantage of opportunities that might lead to a task:

Lisa spotted one of the healthcare assistants taking clean sheets into the patient who had [previously] wanted a wash. Lisa asked if she wanted some help with making the bed but the healthcare assistant said she did not.

She asked any member of staff, even a temporary 'bank' healthcare assistant:

..... Lisa came out of a patient room and shrugged as if to say, well, nothing to do here. She found the bank healthcare assistant [a healthcare assistant from the hospice bank ²⁸ staff] in the IPU kitchen and asked her what she could do. The bank healthcare assistant was getting some ice cream for a patient. Lisa offered to take it and did so. It was for a patient in one of the twin rooms. Two healthcare assistants were changing one of the beds – the bank healthcare assistant, who was by then outside the room, said Lisa could help, but Lisa came out and said that two people was enough and that they did not need her.

Sometimes Lisa found a job to do, but then the task was taken over by staff, for example:

Lisa went into one room to ask a patient if she wanted to sit on the commode and whether she needed two people to help. (She told me that she knew the patient had just had a suppository.) The patient said that she did, and Lisa went to find someone to help eventually finding the assistant physiotherapist, who came to help. A nurse also came to help. Lisa came out of the room telling me that they only needed two and not three people.

²⁸ Temporary workers employed to meet the fluctuating staffing needs caused by staff illness, or increased patient demand (<https://www.bankpartners.co.uk/news/2016/02/what-is-an-nhs-staff-bank/> accessed 11/12/18).

On another occasion Lisa found a job through Gaye, a general volunteer:

She went to find another patient to help – we met Gaye outside one of the rooms – she asked Lisa, ‘Can you help xyz with her dentures?’.

However, even on a ‘busy’ shift, she found it difficult to find much to do as this fieldnote illustrates:

Bella [senior nurse] said that today was busy as two patients were being discharged and two were coming in. ... She asked if Lisa could help with a patient who needed three people to administer care. At this point, the Nurse Manager came over and asked Lisa if she could help with repositioning a patient She went to the room, spending quite a bit of time in there (even though it was supposed to be a quick job). I asked what had happened, and she said that they had to wait for a doctor and then various other members of staff before she could give the patient a wash. She then went in search of the patient who needed three people. At several points during the shift she had to ask what she should do to help, and didn’t seem to be given much even though they were short-staffed.

In this fieldnote she was asked by two different members of staff to do a task without reference to each other. This suggests that there was little planning about what she should do. As I did not follow paid staff, it is difficult to draw further conclusions. However, the fieldnote demonstrates how Lisa’s role was subordinate to those of high-status staff. It also supports Twigg’s (2000) observation above that bodywork, especially dirty bodywork, is low in status.

So far, I have shown how difficult it was for Lisa and Lucy to gain ‘membership’ of the care team. By not attending handover they were not part of the ‘team’ in the same way as the nurses and healthcare assistants, did not have easy access to patient information and lost the opportunity to ‘pair up’ at the start of the shift. This meant that they struggled to gain a foothold in the shift’s work. I suggest, therefore, that the volunteers were being made ‘invisible’.

I noticed that their invisibility was also played out literally. Of the fifteen shifts I observed at Daisy Hospice, the volunteers were included only once in the list of staff ‘on duty’ on the nurses’ station whiteboard, when ‘Lucy – vol’ was added. In my final week at Daisy Hospice another smaller whiteboard was erected in the main IPU area on view to patients and relatives. This listed all the staff on duty by job title (‘nurses’ for both nurses and healthcare assistants, ‘doctors’,

'housekeeper' and 'physiotherapists'). Lucy noticed that her name was not listed. Shortly after, the Nurse Manager added her name under the list headed 'nurses': 'vol: Lucy'. I wondered whether this was for my benefit. The volunteers' 'invisibility' was further emphasised to me by Lucy when she showed me the diary kept in the nurses' station in which she and Lisa noted any days they would not be able to undertake their shifts. She told me that she thought she should indicate when *was* going to attend since staff seemed never to be expecting her.

In observing the difficulties Lisa and Lucy had in finding work, I noticed that Lucy found it easier to find tasks than Lisa. For example, on several occasions Lucy managed to pair up with a particular healthcare assistant. I was puzzled about why her experience was dissimilar to Lisa's. One difference between them concerned how they took breaks. Lisa rarely took one and, when she did, she usually stood in the inpatient unit kitchen chatting to the general volunteers. Lucy, however, always took a break in the staffroom, often with the healthcare assistant with whom she was working. I noticed that during some of these she 'talked shop' with a staff nurse who had also previously worked in the town as a community nurse. Bearing in mind that I followed only two volunteers at Daisy Hospice I speculate that this gave her an 'entry' into the staff team, which Lisa did not have, and may have allowed her to claim membership of the nursing fraternity. Social contact with the nurses was unusual for the care assistant volunteers who tended to chat socially only with the healthcare assistants.

In this section I have used my data to show how the volunteers – particularly Lisa and Lucy – were excluded from the nursing teams, sometimes struggling to find tasks to do, and becoming 'invisible'.

Next, I examine another strategy by which Lisa and Lucy were treated as anomalies, that of suggesting they have a low position in the clinical hierarchy. I have called this 'downgrading,' using the term in the sense of diminishing the value of something or someone.

7.3 'Downgrading' volunteers

In this section I show how the volunteers were positioned at the bottom of the social hierarchy in the nursing team, and how the volunteers dealt with this by 'colluding' with this status in order to 'help the hospice'. I also present examples of volunteers being involved with patients after death. Although this appears to contradict the argument I made in the previous chapter that volunteers

are kept away from death, I show how these encounters reveal how the care assistant volunteers were, in fact, being downgraded. The section is in three parts for readability although there is some overlap: staff downgrading strategies, volunteers justifying their role and dealing with death.

7.3.1 Staff downgrading strategies

The following fieldnote describes an instance where Lucy met senior nurse Bella in the nurses' station at the start of a shift. It illustrates what I interpret as downgrading strategies:

Bella said that she would get someone to do a handover, and called over a healthcare assistant ('Eva') who was walking up the unit. Lucy said she hadn't met Eva before and Bella introduced her: 'Lucy's one of our volunteer nurses – she helps with extra nursing duties'. She suggested that they pair up. She asked Eva to do a handover. She didn't explain the new whiteboard. Eva got her handover sheet from her pocket and went through the patients with Lucy... They went round all the rooms saying hello to the patients. At one, Eva came out and said that the patient had 'messed herself so we will wash her'. They went to get the trolleys required [one for soiled bedlinen and towels, one for toiletries and other supplies]. I sat and waited. When they had finished, she and Lucy took the trolleys back to the sluice and patient bathroom [where toiletries such as body wash and shampoo were stored]. [Somehow Lucy and Eva became separated.] When Lucy went to look for the next job, she met the senior healthcare assistant who told her that that he and Eva were doing xyz [another patient], and suggested that she check on the patient in the end room.

Bella's first downgrading strategy is to delegate 'handover' to a low-status member of staff, a healthcare assistant. Second, although she directly referred to Lucy's status as a nurse when introducing her, Bella also pointed out Lucy's volunteer status, thus 'explaining' Lucy's presence. Third, she 'suggested' that the two could pair up, leaving it open for the healthcare assistant to claim she had other work to do. The healthcare assistant was not known to Lucy and therefore was likely to be a newer employee (unfortunately I did not confirm this). I conjecture that this person had not paired up with another staff member because staff preferred to work with familiar partners (as Eli had indicated when she paired up with someone she already knew well) and was therefore 'alone'. Further, Bella did not specifically give them a job to do. They had to find one by asking the patients, a tactic commonly used by the volunteers. The fieldnote also shows the fragility of the pairing up process for the volunteers as Lucy lost her partner to the higher-ranked senior healthcare assistant and had to start again to find a job.

On an occasion when Lucy had found a place in a pair, she was careful to ‘manage’ this:

When she and the healthcare assistant had finished washing the patient they took the trolleys back to the sluice and bathroom. In the sluice, Lucy said to the healthcare assistant, ‘Right then, where are we going?’. The healthcare assistant said, ‘Let’s do Caradoc’. They went up to the room, but the blind was drawn and the door shut.²⁹ They hung around trying to see who was in there. The healthcare assistant went to knock on the door and Lucy said, ‘You’ve got more authority than me’. The healthcare assistant popped her head in, said ‘Sorry – we’ll come back’, and to Lucy, ‘Doctor’. We waited outside.

Lucy reinforced that she and the healthcare assistant were a pair by pushing for another task with her ‘partner’ (‘... where are we going?’), accepting her lesser status by allowing her partner to have control of where the next task would be. She then explicitly expressed this by saying, ‘You’ve got more authority than me’. This referred to the closed door which could have been sequestering anything from a visiting relative to a deceased patient. She was thus constructing a boundary between ‘volunteer’ and ‘professional’ based on status and authority, one of the three ‘boundary markers’ identified by van Bochove et al. (2018, p. 8) (the others are knowledge and skills, and predictability and reliability – see Chapter 2). Again, my fieldnote illustrated how the bodywork of washing patients was of lower status than the work of other professionals, in this case, a doctor.

Downgrading could also be seen in Eli’s role at Flora House. Despite volunteering in her former role, Eli had lost status now that she was unpaid. For example, on one occasion she served breakfast covering for the ward hostess whose role, as I described in Chapter 6, was at the bottom of the staff hierarchy. She also no longer had access to the ‘forbidden space’ of the treatment room since her fob was now a ‘volunteer one’ as one of the nurses put it. From my fieldnotes:

Eli came out of a patients’ room and said to the nurse that she was having trouble getting a patient to swallow. She asked her for a syringe which she thought she could use to help the patient

²⁹ I described in Chapter 6 the use of closed doors and drawn blinds.

to feed. The nurse said, 'Oh yes, you won't be able to get into the treatment room' [to get a syringe because your job won't work].

Thus, in her new role as *volunteer*, Eli did not have the same status as she had previously, even though she was performing the same role and, I surmise, had been a trusted employee otherwise would not have been taken back as a volunteer.

7.3.2 'Helping the hospice'

In a similar way to the 'general' volunteers I discussed in Chapter 6, the volunteer care assistants 'kept busy', in their case initiating low-status jobs when they ran out of care-related tasks. For example, Lucy checked the stocks of disposable gloves and aprons held in racks outside the patient rooms, replacing those that were new from a store cupboard near the treatment room. She also tidied the sluice room, moving portable commodes to the edges of the room and taking bags of clinical waste to a bin outside. If there were bags of dirty linen, she put them out into the lobby by the outside door. She told me that she saw these 'dirty work' jobs as '*helping the hospice*'. I argue that she was justifying undertaking a task below her professional status by drawing on the discursive resource of volunteering as 'helping out' (see Chapter 2), thus reframing a low-status task in terms of the cultural ideology of volunteering.

Lisa also undertook tasks to 'help the hospice', such as picking up the medication as in the fieldnote above. On another occasion she went to a local pharmacy to collect medication for a patient. Whereas Lucy usually left at around 12.30 pm, Lisa stayed until 2 pm when the hospice's weekly order of controlled drugs was ready. She took this to a hospital near her home – another 'favour' to the hospice. This meant that she often had nothing to do over the lunch period since this was protected time for patients to eat. She filled in by helping the general volunteers serve lunch, on several occasions offering to help patients who required feeding. On a very 'quiet' shift she helped the general volunteers clean out one of the cupboards in the inpatient unit kitchen.

Lisa told me that she volunteered on that particular day of the week because it was the day that staff were involved in a multi-disciplinary team meeting, so she was more likely to be '*useful*'. She told me that when she initially volunteered, she thought she would be '*helping the nurses*'. However, she found that she was in fact supporting the healthcare assistants despite the fact that her nurse status known and sometimes taken advantage of:

The nurses finished [lunchtime handover] and Lisa went over to say that she was going – one asked if she would be able to stay to sit with the patient having the IV medication as otherwise he may pull the line out [he was agitated]. The nurse said that she had already put the cannula in, and that the medication would take about half an hour to go through, but that they would find someone to take over half-way through. Lisa asked what the medication was, and they said that she would know better than they what it was. They said that several of them [i.e. the nurses] were going to the training at 2pm [weekly training session], and that they were ‘short’. [I sat with her next to the patient.] It took about 45 minutes for the IV drug to ‘go through’. Lisa commented to me that she would have secured the cannula differently (although may be she didn’t realise how restless the patient was and it had been done like this to reduce the likelihood of the patient pulling it out), and showed me how she always folded the drip line to make sure all the medication came through but that no air came through the line by mistake. (...) Afterwards (...) she knocked on the treatment room door to pick up the controlled drug order. (...) One of the nurses said, ‘Thank you – you’re a superstar’(...). However, they got her name wrong calling her something similar but which wasn’t correct – they had called her this earlier when she had met them wheeling the drip stand out of the treatment room. She didn’t correct them. We both left. It was 3pm.

In this fieldnote the nurses involved Lisa as an ‘extra’ because they were short-staffed. However, they did not relieve her as they had promised and did not explain the reason for this. Although a nurse thanked her elaborately, she did not know Lisa’s name. I argue that these were all strategies by which staff downgraded Lisa and avoided admitting her into their team. Lisa undertook this task as a ‘favour’ – she could have claimed a prior engagement as the task involved her staying later than her usual end time. She co-operated in order to ‘help the hospice’ suppressing her own status for the ‘common good’, a popular motive for volunteering (for example, Brown, 2011a; Keleman et al., 2017).

Having discussed examples from my data which show staff ‘downgrading’ volunteers and how volunteers ‘colluded’ by accepting their low status as ‘helping the hospice’, I now discuss data which appears to contradict these findings.

7.3.3 Dealing with death – contradicting downgrading?

I argued in the previous chapter that death and dying seemed to be professionalised territory. However, on two occasions during my fieldwork, care assistant volunteers had contact with

patients after they had died which appears to contradict this argument. In one instance Eli undertook 'last offices' ³⁰, preparing the body of a patient who had died before it was seen by relatives. In my extended conversation with the volunteer manager:

I asked what the differences were [between the volunteer and paid roles] - she said that volunteers don't do 'last offices', manual handling, or feeding but could do so with training as the healthcare assistant job description has these things 'with training' added.

As I did not attend handover, I do not know how Eli was allocated this task. Given that there were no other volunteers in the care assistant role at that time, I could also not check whether other volunteers – particularly any that had not previously worked in the healthcare assistant role as Eli had – were given the training required. The inpatient unit was full on this occasion and I noted that Eli was working alone, so I could assume that as she did not have a partner, she had been given the task out of necessity taking advantage of the fact that she had been fully trained.

The other example of a volunteer having contact with a patient after death was when Lucy was asked to check a body in the hospice cold room. From my fieldnotes:

She found them [the healthcare assistants] quickly Lucy asked what there was to do, and one healthcare assistant said that a patient had died [but used a euphemism which I didn't catch – she had a heavy regional accent and spoke softly] and asked Lucy to check on her 'she may be leaking – she's in Ragleth [the cold room]'. (They had this conversation with the healthcare assistant standing in the doorway of a patient's room with her back to the patient, and Lucy standing outside.) She said that if she was leaking, she would come and clear it up, and that the key was the one with the union jack key fob in the treatment room. Lucy said that was fine – she asked me 'is that OK with you?' and I indicated that it was. We went to the treatment room – Lucy said, 'I never know what to do here' [ie how to get in – what the protocol is as it is always locked] and knocked – there were three nurses in there – one opened the door and Lucy asked for the key to Ragleth – the nurse had it in her pocket and gave it to her.

This fieldnote shows how Lucy was trusted to enter the 'inner sanctum' of the cold room. I interpret this as 'welcoming work' (van Bochove et al., 2018, described in Chapter 2) since the

³⁰ The term refers to the care of a body after death.

healthcare assistant would have done this job herself given time. However, Lucy was not required to clear up any leaks of body fluids. The concepts of bodywork and 'dirty work' explained above suggest that this job would be given to those lowest in the hierarchy. However, in this case, the healthcare assistant said she would do this task. Since this would have involved caring directly for a dead body, I argue that such work was part of the 'trained' and therefore 'expert' role of the paid staff so unsuitable for volunteers. In Chapter 9 I explore this idea further using the concept of liminality and the role of the 'ritual expert'.

I turn now to discuss the last strategy by which the volunteers were treated as anomalies, literally removing them from the hospice by sending them home.

7.4 Sending them home

I discussed in Chapter 6 how the inpatient unit general volunteers left early if they ran out of tasks to do and how an 'afternoon' volunteer at Daisy Hospice deliberately did not unload the dishwasher in order to leave the supper volunteer 'something to do'. The volunteer care assistants also left early if there was nothing more to do illustrated in this fieldnote:

Not far into a shift with Lucy, she found the healthcare assistants preparing to wash a patient. Lucy offered to help, but they told her that she may as well go home as there was nothing else to do. One healthcare assistant said, 'I'm paid to do it'. The Nurse Manager came over and said, 'It isn't usually like this'. She said to the healthcare assistants that some staff were attending syringe driver training which meant that they and two of the nurses would be 'on their own'. The healthcare assistants said that they would manage. The Nurse Manager left. One of the healthcare assistants thought she could go to the training [as Lucy could help with the patient] but changed her mind, and said again that Lucy may as well go home. 'We've got the student (nurse)', one of them said. Lucy asked again whether they were sure. Eventually, she left. It was 9.25 am.

After this incident I asked Lucy whether she rang the hospice before leaving home to find out if they needed her. She said that she had not thought of doing so but added that it was difficult to ring before 9 am (when the Ward Clerk started work) as no one answered the telephone. I argue that the distinction drawn in this fieldnote by the healthcare assistant between volunteers and staff based on their paid and unpaid statuses shows staff performing 'demarcation work' (van Bochove et al., 2018). It creates a boundary between staff and volunteers based on this status.

The staff preferred the help of the student to the trained nurse even if it meant missing out on a training opportunity. It should be noted that the hospice would have had some contractual obligation towards the student nurse, who was completing a placement as part of her nursing degree. Therefore, there was 'capital' in involving the student but not the volunteer. The Nurse Manager's intervention shows that Lucy might be welcome when the unit was busy; she was also justifying Lucy's presence as useful additional support. Involving volunteers as 'extra' was also alluded to on another occasion when Lucy left early:

She said [to the healthcare assistant she was working with] she would go home as there wasn't anything else to do. The healthcare assistant said that normally they were rushed off their feet Lucy left.... It was 10.30.'

At Flora House Eli also left early if there was not much to do.

In this section I have discussed how the volunteers were sent home, removing them from the hospice altogether. The section has also highlighted the importance of status based on being paid or not, and I return to this topic in Chapter 9.

7.5 View from the other side: why involve volunteers?

The difficulties faced by the volunteer care assistants raised the question of why volunteers were involved in this role in the first place. I discussed this with both the Head of Clinical Services at Flora House and with the Nurse Manager at Daisy Hospice. I found them both to lack a realistic understanding of the role, telling me that they were keen to involve volunteers in this way and believed that the practice was working well. The Nurse Manager told me that since initiating the role about eighteen months previously around six volunteers had been involved, but all had resigned for '*one reason or another*'. I could not encourage her to elaborate on this. At Flora House the Head of Clinical Services told me that a senior nurse who had recently retired was planning to return as a volunteer care assistant. Towards the end of my observations at Flora House I learnt that this person had lasted only one shift. This suggests that volunteer retention in this role may be problematic. It contrasts with the long service of volunteers I met in general volunteer roles in the day hospices and inpatient units, two of whom at Daisy Hospice had been involved with the organisation since its inception.

When I asked the Nurse Manager what staff thought about involving volunteers, she emphasised that they had a high regard for them saying, *'Although it is understood that we can't rely on them, they are not always able to be here'*. Taylor (2005) explains how 'volunteer' came to be attached specifically to middle-class women who provided unpaid support to organisations such as hospitals, whereas others who were also unpaid, such as doctors or trade union officials, were not so called. Therefore, I argue that the Nurse Manager's comment draws on a discourse of volunteering as a middle-class leisure activity. It also reflects one of van Bochove et al.'s (2018) 'boundary markers' (p. 8) between paid staff and volunteers, that is, predictability and reliability. The Nurse Manager's view was not held by a nurse who Lisa partnered to wash a patient, after which Lisa reported to me that the nurse had said, *'I don't know why you're here'*. *'That says it all'*, Lisa told me. In other words, in Lucy's eyes, the nurse did not understand why a volunteer was involved.

As I suggested in Chapter 6, volunteering is outside the frame of the medical model. Compared with professional volunteers in the day hospice, who are the topic of the next section, the care assistant volunteers had particular difficulty negotiating their role which, unlike that of other volunteers, directly overlapped with that of staff. Drawing on Douglas (1966/2002), I argue therefore that these volunteers were 'dangerous'; their unpaid volunteer status directly violated the cultural order of nursing, 'disrupting' the hierarchical world of the clinical team. Furthermore, their role involved approaching the life-death boundary which, as seen above and in Chapter 6, was professionalised territory.

Before leaving this section, I point out that the Nurse Manager also highlighted an important structural issue with involving volunteers as nurses rather than as healthcare assistants. The institutional insurance required regarding administering drugs is available only for employees (that is, those who have contracts). This re-emphasises that volunteers are outside the professional boundary of care.

I turn now to discuss professional volunteers in the day hospice.

7.6 Ambiguities: day hospice professional volunteers

In Chapter 5 I highlighted differences between the professional and general volunteers which made the former appear more like hospice staff in this setting: they wore uniform, staff often

gave them more patient information than the general volunteers, and they could interrupt activities between the general volunteers and patients. Furthermore, like staff and unlike the general volunteers, their full name appeared on their badges (discussed in Chapter 4 section 4.3). This section will examine the roles of these volunteers in more detail. It will show how they worked separately from staff and without supervision to make my argument that they were treated simply as a type of staff group and, therefore, as ambiguous in contrast to the care assistant volunteers. I begin by describing the professional volunteers' involvement in the day hospice sessions.

At Flora House, as soon as the patients were seated after arrival, the volunteer complementary therapists started to work their way round the group asking each if they would like a treatment (hand or foot massage, reiki session or aromatherapy massage). Patients who requested a foot or hand massage were treated where they were sitting, the therapists maintaining a conversation with them while they worked, otherwise they were taken to one of the therapy rooms. I noticed little interaction between the volunteers and staff and, when no more patients wanted treatments, the volunteers left, always before lunch was served. They took no part in the 'hospitality' aspect of the sessions.

At Daisy Hospice a more formal system operated as described in Chapter 5. While the general volunteers started to engage with the patients, offering tea and coffee, and initiating banter, the professional volunteers stood to one side of the room waiting to find out which patients wanted their services:

I asked volunteer Steph if I could follow her as much as possible. She said she was waiting to know which patient wanted a treatment first. I asked her if she found it frustrating, and she said that there was a lot of wasted time.

Daphne, the 'exercise' volunteer, also found it frustrating to have to wait. She told me:

... that the senior nurse [who ran the sessions] had asked her not to start exercise until 10.30 am as the patients needed a rest after coming in – this means that it can be difficult to fit everyone in as patients sometimes have appointments for other things during the morning, such as seeing a doctor.

They were not asked by staff to 'fill in' with 'general' duties, and thus treated like staff with a specific role, albeit with little control over their schedules. As at Flora House, the professional volunteers all left before lunch (other than the art therapist who I consider below) and, I noticed, did not take part in the social aspects of the sessions. I argue that the professional volunteers were performing boundary work (Gieryn, 1983). The boundary between being a professional and a general volunteer was fragile and could be maintained only by remaining in a 'professional' role. By contrast, staff's professional boundary was protected by their paid status. They offered professional skills and took part in the social aspects of the sessions, joining in with banter at the lunch table, for example (described in Chapter 5 section 5.5.2), slipping easily between clinical and social roles. In Chapter 5 I gave an example from my fieldnotes where a volunteer had been chatting with a patient, his wife and a nurse, but left the group when they started to discuss 'paperwork'. As well as showing how the general volunteers were not involved in clinical matters, this also shows how the nurse in this example moved between social and clinical roles.

I suggest that staff supported these volunteers in the maintenance of a 'professional' boundary because, unlike the volunteer care assistants whom I discuss later in this chapter, the complementary therapists undertook work which was not part of the clinical staff's role. The bodywork the complementary therapists undertook focused on integrating body and mind in the pursuit of greater wellbeing (Twigg, 2000) and was therefore an important part of the production of 'living' in the hospice, but not part of the medical model of care. Whereas, as I discussed in Chapter 2, research shows that staff can feel that their positions are threatened by volunteers (for example, Field-Richards & Arthur, 2012), I argue here that these volunteers were tolerated by staff as ambiguities and therefore simply allocated to the category of 'staff'. The two actor groups – staff and professional volunteers – simply co-existed.

However, Melissa, an art therapist at Daisy Hospice, did not stay within 'professional' boundaries and crossed into the territory of the 'general' volunteers. Although she was not involved with bodywork, I include her in this analysis since she offered skills for which a professional qualification was required. Her example showed the importance of maintaining the integrity of the professional-volunteer boundary.

When I first met Melissa I was confused by her role. In the first week I observed, the patients worked on an art project which Melissa had designed. From my fieldnotes of the next session:

I asked Melissa if she was starting a new art project today. She said that she only did that when asked and didn't initiate it, as she was really an art therapist and not really there to do creative art.

When I questioned her further, she told me that she did not get 'used' much in her professional capacity which she found frustrating. In the time I observed she did not undertake any art therapy sessions with the patients. Like the general volunteers, she wore street clothes but did not wear a tabard apron, thereby distinguishing herself from them. Although she did not involve herself with serving drinks or lunch, she helped patients take part in completing the word puzzle on the flipchart. Over the time she had volunteered she had formed a close bond with a patient with Parkinson's disease, who she fed at lunch time. She spent a great deal of the sessions sitting with this patient, rubbing his hands to warm them up and reading the newspaper to him. I noticed that staff treated her like a general volunteer. From my field notes describing a pre-session briefing:

Back in the day room, Melissa had arrived and was sitting on the chairs where the briefing takes place. I said hello, and sat down with her. We had a brief chat. ... The two complementary therapists arrived The rehabilitation assistant arrived, but no general volunteers. Daphne arrived, and there was a short conversation The senior nurse [giving the briefing] went to check in the office which [general] volunteers were expected. She came back and said to Melissa, 'Where are the ones like you?'. Melissa grunted. My impression was that she was not very pleased as she doesn't like to be lumped in with the 'general volunteers'.

I noticed that Melissa always left the hospice at the same time as the patients, not staying with the other volunteers to clear up. She told me that she was unhappy with the fact that she was treated as a general volunteer and not involved with art therapy. However, she did nothing to change the situation. I wondered why she did not stop volunteering, but was wary of asking her this directly because I was concerned that I should maintain as neutral a stance as possible, and that by asking her I would 'put ideas into her head' and thus change the field. I interpret Melissa's unhappiness by arguing that, in crossing into the role of the general volunteers, she could not maintain her fragile 'professional' boundary. She had created a role for herself as a particular patient's carer maintaining her usefulness to the hospice. However, in doing so, she seemed to have sacrificed her 'professional' role and thus experienced considerable ambiguity. In Chapter 9, I consider Melissa's role again through the theoretical lens of liminality.

Whereas Melissa reduced her status by taking on 'general' volunteer tasks, by contrast, Ken, a general volunteer at Flora House who supported the drop-in sessions, offered his expertise as a qualified hypnotherapist. The senior nurse who ran the day hospice told me that she did not know about this skill when she recruited him but was happy to accept his offer to provide this service. I noticed that he seemed to have a higher 'status' with the day hospice staff. For example, they sought his opinion above that of the other volunteers about various matters, such as about how to arrange the tables for the Christmas party and what kind of covers to buy to protect wooden patio furniture kept outside. If he arrived late for a session, they always made sure they told him about any patients they were expecting which was not the case for the other volunteers. Unlike Melissa, Ken told me that he found his volunteer role fulfilling. Drawing on van Bochove et al. (2018) (whose approach I outlined in Chapter 2) I argue that staff had undertaken 'welcoming work' by inviting an individual volunteer into their professional domain. The concept of 'welcoming work' is based on *staff* initiating an alteration in their professional boundaries, not volunteers. Ken's volunteer-professional status may have been more 'successful' than Melissa's because it had been sanctioned by staff, whereas Melissa had taken on her 'general' role herself.

There may also be an explanation for Ken's higher 'status' based in gender but, given the low numbers of male volunteers I observed, I do not have sufficient data to explore this. I briefly consider the gendered nature of volunteer roles in Chapter 9.

In this section I have shown how the professional volunteers in the day hospice – mostly complementary therapists – are treated in a similar way to staff. Since the skills they offered were not part of the usual role of staff within the medical model, they posed no threat to staff who, drawing on Douglas, treat them as an 'ambiguous' type of 'matter out of place'. However, their 'professional' boundaries are more fragile than those of staff and I showed how they perform boundary work to maintain this status, notably by not involving themselves in the social aspects of the sessions.

7.7 Summary

In this chapter I have drawn on Douglas' (1966/2002) explanation for dealing with 'matter out of place' to show how staff used various strategies to treat volunteers who offered their professional skills as either anomalous or ambiguous. I showed how the volunteer care assistants were subject to various strategies to exclude them, keeping them out of the staff team,

‘downgrading’ their status and sending them home. I argued that these volunteers, whose roles overlapped with those of paid staff and crossed the boundary into what I have previously suggested was the professionalised territory of death and dying, violated the cultural order of nursing since volunteers are outside the professional boundary of care.

I then described the professional volunteers in the day hospice, who by contrast with the care assistant volunteers, undertook their roles in parallel with staff. I argued that staff treated these volunteers as ambiguous and allocated them to the category ‘staff’. These volunteers posed no ‘threat’ to staff since the bodywork they undertook was not typically part of the clinical care provided by the staff and were therefore ‘*complementary not substitutive*’ (Sevigny, 2010, p. 743). However, I also suggested that these volunteers performed ‘boundary work’ (Gieryn, 1983) to protect their ‘professional’ status. I compared two volunteers, Melissa and Ken, showing what happened when the boundary between ‘professional’ and ‘volunteer’ was disturbed. I drew on van Bochove et al.’s (2018) concept of ‘welcoming work’ to explain how a volunteer in a professional role could be made ‘safe’.

Douglas argues that crossing boundaries risks a loss of power (Douglas, 1966/2002). Staff, secure in the clinical hierarchy, could perform all roles, both clinical and social. Volunteers did not share this security. There was less ‘danger’ to staff when this work was ‘complementary’ but much more when the work was ‘substitutive’. This supports previous research showing that staff can feel threatened by volunteers (Field-Richards & Arthur, 2012) particularly those with professional qualifications (Payne, 2002) (see Chapter 2). The comment from a healthcare assistant above, ‘*I’m paid to do it*’, draws attention to the importance of difference in pay status between volunteers and staff in positioning volunteering as an activity which should not take the place of ‘professional’ labour. This discourse acted as a boundary constraining the role (Ganesh & McAllum, 2009) which may explain why, when volunteers acted as professionals, they were ‘matter out of place’.

In the next chapter I return to the production of ‘living’ to consider the bereavement team volunteers.

Chapter 8. Bereavement team volunteers: return to 'living'

In this chapter I consider the bereavement team volunteers, returning to the topic of the production of 'living' which I discussed in relation to the day hospice in Chapter 5. Using Hockey's model of the hospice movement's construction of death and dying as a process (see Chapter 2 and Appendix A), I argue that relatives were helped to return to 'living' following a patient's death. Further, in Chapter 2, I outlined Froggatt's (1997) suggestion that in hospice culture, bereaved people are in a liminal state passing through bereavement back to living. Within this conceptualisation, grief can be identified as disorderly since, as *liminars*, bereaved relatives are 'betwixt and between' (Turner, 1967, p. 71) death and life and, therefore, ambiguous. Drawing on Douglas (1966/2002) they are thus potentially threatening at both social and individual levels (Littlewood, 1993).

As I described in Chapter 2 the hospice movement has always considered bereavement care to be an important part of its remit (Saunders & Clark, 2002). However, services rely on volunteers (Field, Payne, Relf, & Reid, 2007, p. 434) whose involvement, rather than that of mental health professionals, underlines the focus on supporting bereaved relatives to cope more effectively with their experience of loss rather than on 'therapy' (Relf, 1998). Relf (1998) points out that the involvement of volunteers – 'ordinary people' (p. 62) – emphasises that grief is normal and avoids the potential stigma associated with mental health interventions, such as counselling. In what follows I show how the tension between grief as 'disorderly' and the need to restore ontological security (Seale, 1998a, p. 196), alongside the 'un-professional-ness' of volunteers, produces contradictions in the volunteer role.

As explained in Chapter 3 I followed bereavement team volunteers at Flora House only, observing two weekly activities, 'Coffee Time', for which the volunteers acted as 'hosts', and 'Telephone Support'. My data show how the role was concerned with supporting the hospice in its efforts to maintain the life-death boundary ensuring that 'living' was produced partly by keeping death out. Although these volunteers had no contact with dying patients, they were subject to a high level of supervision and training compared with volunteer roles in other settings. I will show how the role was constantly monitored by a member of staff, Gloria, who undertook what van Bochove et al.

(2018) call 'demarcation work' (see Chapter 2) positioning the volunteers as non-professionals, and herself and other staff as professionals. However, counterintuitively, the bereavement volunteers had more flexibility and autonomy than volunteers in other settings. In this way, contradictions were played out.

The chapter is in six parts. I begin with a brief survey of bereavement models to contextualise the hospice approach to bereavement care. I then examine the written information given to clients, that is the 'script' for this care, showing how 'living' was produced. In the third and fourth parts I introduce Coffee Time and Telephone Support respectively showing the volunteer role in supporting 'living'. Next, I explore the topic of death being handled by experts and the 'demarcation work' undertaken by Gloria. Finally, I explore Gloria's 'welcoming' work' (van Bochove et al., 2018, p. 11) and the flexibility enjoyed by the volunteers, thus demonstrating the problematic nature of the volunteer-professional boundary in this group of volunteers.

8.1 Bereavement models

The feelings of loss and grief associated with bereavement have been conceptualised in different ways (Small, 2001) but can be categorised into three main approaches: psychological, sociological and models of stress and coping (Payne, 2008). Western approaches have tended to medicalise grief with psychological models dominating practice (Howarth, 2007). These frame grief within a biomedical model of illness and recovery. Freud was the first to attempt a scientifically rigorous account (Árnason, 2007; Freud, 1917) resulting in an explanation which emphasised the unhealthiness of 'unsuccessful' grieving. Later, Lindemann (1944) developed the idea of grief as a 'syndrome' with a 'normal course' and therefore with the potential for 'morbid' 'outcomes'. This conceptualisation of grief as *work* and as a *process* of transition (Howarth, 2007, p. 197) has been hugely influential. It has led to the development of stage models of grief (for example, Parkes (1972), Kubler-Ross (1969)), within which bereaved individuals undertake 'tasks' in order to 'recover', such as acceptance and adjustment (Worden, 1982). Moving away from a psychodynamic construction of grief, Stroebe and Schut's (1999) 'dual-process' model draws on psychological models of stress and coping to recognise the importance of social factors in grief. Nevertheless, the model focuses on psychological adaptation (Howarth, 2007). Sociological models, meanwhile, recognise the experience of loss as socially constructed (Howarth, 2007). Grieving is seen as part of the life course, rather than as a medical event, and framed in terms of transitions and social networks (Walter, 1996). Klass et al. (1996) suggest replacing traditional models of grief with a 'continuing bonds' model which proposes that the bereaved person

continues a relationship with the deceased. As I will show, the volunteers I followed drew largely on a stage model of grief during their encounters with clients.

Having briefly outlined key bereavement models, I begin my exploration of the bereavement team volunteers at Flora House by examining the written information given to bereaved relatives. I argue that my data show how these formed the institutional 'script' which framed the volunteer role and which was focused on producing 'living'.

8.2 Preparing the performance: the script

The hospice bereavement service 'script' for the performance of 'living' included a flier for each of the activities offered (Coffee Time, Telephone Support and a pub meeting (which I did not observe)), an advice leaflet for bereaved people and 'guidelines' given to Coffee Time clients. These were all produced by the bereavement team staff. At the first Coffee Time session I observed Gloria showed the volunteers the fliers which had recently been re-designed. These were A5 in size with a colour photograph in the top half and a brief description of the activity underneath. The photographs suggested 'life' and 'living' rather than images associated with bereavement, a point which Gloria emphasised:

Gloria reiterated that they liked 'cheerful' photos on the leaflets. she pointed out that they had a photograph of a plate of fruit tarts on the 'Coffee Time' leaflet, rather than 'lilies or something'.

While the Coffee Time flier used food to suggest living and that it was time to treat yourself, the others invoked the restorative power of nature. The Telephone Support notice showed a red telephone box set among trees in full leaf, while that for the pub meeting pictured the pub used for the meeting against an almost cloudless blue sky. The bereavement service flyer showed a wooden fingerpost indicating different footpaths set against a field of oilseed rape in full flower creating a bright yellow background against a cloudless sky with leafy trees on the horizon. The photograph on the advice leaflet showed a stone 'pack horse' bridge over a stream with verdant trees in an upland hill setting. The fingerpost and bridge could be seen as symbolic of moving into a new life, exploring new horizons in a sunlit world. The hillside setting also suggested timelessness and continuity, focusing the bereaved person on moving forwards through bereavement towards a new future. This idea was supported by the text of the fliers. That for Coffee Time read:

‘Why don’t you join us, buy a drink, a piece of cake and enjoy a chat in the relaxed surroundings of [Department Store ³¹] Café.’

The pub meeting flier was similarly worded, substituting *‘something to eat’* for cake. The focus of these activities was therefore on *joining* us – that is, the living – for enjoyment and relaxation.

The ‘guidelines’ given to new Coffee Time clients described the *‘aims of the group’* including that it was *‘an occasion for a weekly get-together’* for bereaved people and that it was to *‘enable’* clients *‘to enjoy the company of others’* who *‘share the same experience of being the survivor after the death of someone close to you’*. ‘Enjoy’ and ‘survivor’ express living. The leaflet also talked about the role of the volunteers:

‘Bereavement Support Volunteers are always around ... ‘ they ‘stand back ... but are available to talk to ‘ this is a ‘social occasion, but do remember if you are feeling sad, or down, you can always ask ...about the different forms of support available...’

The volunteers were therefore available, I suggest, when clients’ feelings threatened to displace ‘living’. The Telephone Support flier also made this clear:

‘Telephone Support offers the opportunity for you to talk to one of our trained bereavement volunteers. Whatever you’re feeling, they are there to listen and support’.

Unlike the socially-focused events, which emphasised the activities of living, this leaflet acknowledged that clients may be feeling a whole range of emotions. It also made it clear that the service was provided by volunteers. Thus, the focus was on *support* not on therapy (Relf, 1998) but the client was ‘safe’ even if their feelings were out of control since the volunteers were *trained*. This point was emphasised by the small print included on all the leaflets:

‘All feedback received from our volunteers is subject to normal confidentiality guidelines. However, if any information given to a volunteer raises a concern regarding vulnerability or safety of you or

³¹ Name removed to preserve the anonymity of the hospice.

another person, then they have a duty to pass this concern to the [Gloria's job title] at the Hospice. All volunteers have enhanced CRB checks.'

Referencing institutional/statutory procedures together with the fact that volunteers were *trained* presented the service as 'professional'. Later in this chapter I examine the 'demarcation' practices undertaken by Gloria which show how the volunteer-professional boundary was ambiguous.

While the social and support sessions offered clients the opportunity to re-join the 'living' with people (volunteers) to contain any chaos, the advice leaflet suggested that grieving was a process and was time-limited. It acknowledged that:

'The first year or two after a death can be stressful as they are full of 'firsts' which may be difficult (...) birthdays, anniversaries and holidays serve as reminders (...).'

It also suggested joining groups and clubs, meeting friends, arranging activities and taking up new hobbies. In other words, while it allowed some grieving and memorialisation activities, these were to be contained within the first two years after a death and then the prescribed focus was on moving forwards, re-joining the living and starting life again. It also contained some contradictions. For example, it described grief as '*natural and normal*' but also as idiosyncratic, since clients should grieve '*at your own pace*'.

In sum, in this section I have described the institutional 'script' for the bereavement team activities to show how the printed information given to clients focused on moving forwards and re-joining 'living'. The script positioned the volunteer role as supporting clients in dealing with potentially chaotic emotions and I explore this further in the subsequent sections.

I argue therefore that the volunteer role involved monitoring the life-death boundary and I turn now to explore how this was done at the Coffee Time sessions which, as I have indicated elsewhere, took place in the café of a local department store.

8.3 Coffee Time: maintaining the life-death boundary

This section begins by drawing on my data to consider the 'set' or space within which the sessions took place. I then show how the volunteers acted as 'hosts' and how, in doing so, they helped to

prevent death from intruding on the sessions. I also describe Gloria's role in supervising the volunteers.

The department store café occupied a large area, roughly half of the top floor. Coffee Time took place at the far end of this space, furthest from the serving area, escalators and lifts. The space was bounded by a wall and windows, and was divided from other sitting areas by a low wall. It contained around eighteen two-person tables. The separation of the space from the rest of the café reminded me of the sequestration of death 'performed' by the hospice buildings themselves which I described in Chapter 4. The volunteers rearranged the tables nearest the back wall of the room together to form two larger tables, one for around ten people and the other for eight. From my fieldnotes of the first session I observed:

I arrived 9.50, bought a coffee, and found the two volunteers who had already arrived, Liam and Shona (Gloria had told me where they would be and I could see them looking round for people). They stood out as neither had drinks. The cafe was largely empty. I asked them if they were from Flora House ... and explained who I was.... They had already arranged the tables each of which was designed for two people to sit opposite each other. Liam had moved two tables together to create larger tables, using all the tables along the end wall of the café area which had a long bench seat fixed to it. (...) He explained that they liked to have the tables turned through 90 degrees to reduce the distance between people sitting opposite each other, as some of the clients found it hard to hear one another.

After a short while, Bethany arrived carrying a box file which she put on the table. (...) Out of this she took some laminated A5 folded 'Coffee Time' notices which she slid into plastic menu holders (...) She placed them on some of the nearby tables. She was wearing a Flora House volunteer badge on a lanyard round her neck. Neither Liam nor Shona were wearing these (...). Gloria arrived, took orders for drinks from Bethany, Liam and Shona and went to get them. Liam took a laminated 'Flora House' sign and went to stand at the top of the escalator. After about fifteen minutes Shona took over. Liam told me that this was to direct 'new' clients to the group.

Thus, the volunteers acted as 'hosts' for the sessions, preparing the seating and putting out signs, then standing near the top of the escalators to welcome new clients.

The sessions proceeded in a similar way. Most clients arrived in the first hour, joining the group once they had bought refreshments. In the time I observed between fourteen and twenty-two

people attended. The volunteers and Gloria sat at a separate table at right-angles to the client tables which they had 'reserved' by leaving their coats on the back of the seats. I sat with them, taking the opportunity to ask questions.

From my observations I suggest that the volunteer role focused explicitly on monitoring clients for expressions of grief. In my extended conversation with Gloria she explained the volunteers' role at Coffee Time as *'Sitting with clients from time to time to 'monitor' conversations'* since *'It doesn't look good if someone was crying'*. She did not like the volunteers to sit with their backs to the clients (although I noticed that they did) because she wanted them to watch them in case anyone became upset. This 'policing' is illustrated by an example from my fieldnotes:

There was one new person – an older man. Bethany went over to give him one of each of the hospice leaflets about the different events held for bereaved families. (...) Gloria or Bethany spotted that he also had the order of service from his wife's funeral. They were not happy at this. Gloria said that they liked to keep things light and to focus on looking forwards, and they discouraged clients from bringing these. Liam moved to the table where the man was sitting to tell him that they didn't want clients to bring such things. Later, when he'd come back to the volunteer table, he said that he'd said something and that the man 'had understood' and that the man had slipped the order of service under the leaflets he had been given.

I found the team's reaction to the newcomer's action surprising and wrote in my fieldnotes:

I was shocked at their 'outrage' at the new client's bringing his wife's funeral order of service. To me, this was his passport into the group: his proof of membership. He may have thought he would be asked about his wife to 'prove' his membership credentials (...) Gloria and the volunteers kept an eye on him and noticed that he was integrating well.

Thus, the volunteers helped to patrol the boundary between life and death, keeping death and its association with sadness away from those who were being brought back to 'living'. Volunteer Ursula explained it to me as *'keeping an eye on the conversations to make sure they aren't gloomy'*. In terms of the concept of hospitality, as guests, they were expected to 'behave' (King, 1995) and 'collude' with the production of living (Goffman, 1959/1990). Goffman argues that a successful performance requires the audience to collude in the act.

Gloria directed the volunteers during the sessions, for example, ensuring that they took their turn holding the sign at the top of the escalator or sitting with the clients. From my fieldnotes:

She asked Frances to go and mingle with the clients – she said she wanted to increase the amount of time they did this. Frances got up to sit with the client (...). Gloria noticed that Frances wasn't moving along the line of clients particularly quickly – she likes the volunteers just to mingle briefly to check that conversation is up-beat, and then move on.

On one occasion she noticed that there were two volunteers at the top of the escalator. She told me:

'I'm going to do a little saunter – it doesn't look very good over there to have two volunteers for people coming up'.

Gloria told me that *'the volunteers run the sessions'* but that she attended *'to make sure the volunteers don't just sit around and chat to each other – [otherwise] they would revert to being volunteers'*.

By 'reverting to volunteers' she meant that the volunteers would regard the sessions as an opportunity for a social event for themselves rather than as a role to be undertaken involving specific tasks. I argue that Gloria was drawing on a discursive resource of volunteers as amateur and lacking professionalism. I described a similar occurrence in Chapter 4 about a volunteer manager's view of a volunteer receptionist. I discuss this view of 'volunteer' further in Chapter 9. However, there was another explanation for volunteers' 'social time'. Despite Gloria's reminders to dip in and out of the clients' conversations, in most of the sessions I observed the volunteers spent a great deal of the session chatting among themselves. Volunteer Barbara told me,

'...they [the clients] don't like it when we sit with them'. Gloria said, 'No, we remind them of death'.

Volunteers reiterated this on several occasions during my observations. Iris told me, *'They don't like talking to us'*, and Ursula told me that:

'(...) one of the clients had said that they liked to talk without the volunteers in the group as the volunteers made them remember they were bereaved but just talking to other clients helped them to forget.'

At one of the sessions close to the memorial events, the volunteers discussed the event with Gloria:

Toni said that they should have some nicer tissues. Gloria said, yes, as the standard blue boxes remind people of the hospice.

This supports Gloria's comment that bereaved relatives did not like coming to the hospice as it reminded them of their relatives' deaths. As well as illuminating possible tension in hospice ideology in caring for both the dying person and the relative after the patient's death, it suggests that the clients themselves 'resisted' the intrusion of death. It is noteworthy that, other than some one-to-one sessions, activities for bereaved people were held outside the hospice buildings in spaces associated with 'living' and community, a café and a pub. This practice suggests that the hospice building was 'contaminated' by death and thus, perhaps, inappropriate as a setting for helping relatives from death back to life.

During the sessions Gloria placed particular focus on helping new members to integrate into the group. As in the fieldnote above, when a new client brought the order of service from his wife's funeral, 'uninitiated' patrons were potentially 'dangerous' since they could inadvertently allow death into the sessions (Douglas, 1966/2002). In one session she gave the following specific instructions to the volunteers:

'With new people, introduce them to the group and then sit for a while to make sure they are integrating. Maybe take them to that end (indicating the clients sitting at the far end). Also, I want you to go and spend a few minutes with each small group (...). Later she repeated the instructions she'd given when Toni came back from standing at the top of the escalator. At this point, Bethany had gone to sit with some of the clients. Gloria said, 'Like Bethany is', when she repeated the instruction about sitting with the clients from time to time. Toni said they needed to know who people were and to get to know them.

I saw the importance of ensuring that clients integrated in another session:

There was one man clearly on his own, who had originally been included in a conversation but was now not talking to anyone. Gloria noticed him and was keen to keep an eye on him and go over to chat to him if the situation continued. Eventually, a woman arrived and sat near the man – Gloria said that this woman was good at including everyone in conversation so didn't go over herself, or ask someone else to.

On one occasion, when Gloria was unable to attend, her colleague Tina attended in her place:

[Volunteer] Iris asked why she had to be there, and she said 'in case there is anyone new'.

This suggests that new clients needed to be the focus of professional attention to ensure their appropriate acculturation into the group, although in the sessions I observed, clients were welcomed by the volunteers only after being prompted by Gloria.

Symbolic of the 'success' of the group was the '*budding romance*' (as Gloria put it) between two clients who were pointed out to me on several occasions when they left the sessions together. Gloria told me that they were both interested in becoming volunteers themselves. She also told me that:

She'd seen one of their former clients with a new partner in the supermarket, and they had briefly acknowledged each other. My impression was that this was a 'successful' outcome for the bereavement team.

Although I did not specifically ask about what constituted 'success' for the bereavement team, finding a new partner following a bereavement fits a stage model of bereavement. The new relationship is symbolic of new 'life'. The bereaved person is reintegrated into society and thereby 'living'. Using a rites of passage model, Littlewood (1993) suggests that undergoing another rite of passage, such as a birth or re-marriage, restores someone to a full position in society following a bereavement.

In this section I have shown how the bereavement team volunteers helped to produce 'living' in the Coffee Time sessions by patrolling the life-death boundary to ensure that death did not leak into the sessions. As with their counterparts in the day hospice, the bereavement team volunteers' role can also be seen in terms of the concept of hospitality (King, 1995). They acted as hosts, welcoming new guests and ensuring that the guests enjoyed themselves by making sure

they integrated into the group. I have also described Gloria's supervisory role which begins to delineate the volunteer-professional boundary which I develop later in the chapter. I have also suggested in this section that new clients required 'professional' attention because of their potential to create disorder by allowing death to 'leak' into the sessions. I continue this idea in the next section where I describe Telephone Support showing how death had to be handled by an 'expert'.

8.4 Telephone Support: ensuring 'living'

As with Coffee Time, Telephone Support also focused on producing 'living', although since the calls involved openly acknowledging that the client was bereaved, death could not be totally sequestered. The volunteer role involved telephoning bereaved relatives (who had been previously identified by the hospice staff during the patient's illness) to offer support and to invite them to the team's activities. During my observations, up to four people helped to run the weekly sessions which were also supervised by Gloria. She told me she had established the service two years previously and hoped to expand it so it could be offered to more people in a patient's social network than was currently the case. During the sessions Gloria made support calls herself or undertook one-to-one sessions with clients in another part of the hospice. As the sessions took place in the evening, the volunteers sat at desks in Gloria's office which she shared during the day with other members of staff in the social support service. The volunteers therefore had to enter usually 'forbidden' staff spaces (Lefebvre, 1974/1991, p. 193). From my fieldnotes:

I went up to Gloria's office. The room is on the first floor; the stairs are marked 'staff only'; the corridor is quite narrow and this is clearly the older part of the building. Gloria's office is small, oblong, with the door to the corridor in one of the shorter ends with a window in the wall opposite. The window overlooks the lake. I commented on the view and Gloria said, she'd been offered an office downstairs, but she wanted to keep the view, 'that's our sanity', she said. Along the left-hand long wall are three small desks, each against the wall, opposite which are plastic drawers with children's craft materials, with shelves above. There is a filing cabinet in the corner near the window, next to which is a door leading to smaller office with two desks. Each desk has a computer screen and telephone, and piles of files etc. There are notice boards on the walls above each desk in the main room. The walls are covered in woodchip wallpaper, painted magnolia.

There was space in Gloria's office for two volunteers, or three when Gloria undertook one-to-one sessions. Therefore, a second office along the corridor was used which Gloria had to open as it required a code to be entered on a key pad to unlock it, emphasising that the volunteers did not 'belong' in these spaces; this was not their normal 'place of abode' (Lefebvre, 1974/1991, p. 193, see Chapter 4). Volunteer Dana, who undertook administrative work for Gloria, also had trouble accessing the virtual space of the hospice computer system. From my fieldnotes:

Dana arrived (...) Gloria asked her to use a desk in the smaller room – they had a conversation about logging on – Gloria had to log her on as she's waiting to be given a logon of her own, '(...) because I'm a nobody' she said.

Her nihilistic comment that she did not have her own logon 'because I'm a nobody' emphasised the lack of 'belonging'.

I sat behind the volunteers listening to their conversations. Obviously, I could hear only one side of the conversations. I noted that volunteers made two types of call: 'initial contact' calls and 'support' calls. Extracts from fieldnotes explain how the sessions ran:

Gloria gave each volunteer some client notes – blue forms with further notes stapled to them. Each volunteer wrote in the notes after each call. Gloria explained that they were a bit behind with first contact calls as the number of volunteers had fallen, and they focused first on regular support calls. She gave each volunteer an A5 form where they could record the number of calls made (...) I asked the third volunteer about the stats sheet – it is headed 'Telephone Sheet for Stats' and the volunteers make a mark for each call – either 'initial contact' or 'support call' with an additional column for each for 'couldn't make contact'. There was a row for each week.

The volunteers left a message if someone was out (and had an answering machine) explaining that someone would call again next week. They only did this up to three times – the third time they explained that they didn't want to keep hassling the person, but if they wanted support they could ring the hospice, giving the number and extension number.

The volunteers started calls by introducing themselves as 'xyz from the bereavement team at Flora House' and did not mention that they were volunteers. They then asked the client how they were. I could not hear the reply, but the volunteers commonly responded to it by saying, 'It's

early days yet', 'It's only been a while' or 'When was the funeral? Oh, that's quite recent'. In my fieldnotes I wrote about volunteer Nell, who was the most experienced member of the team:

Nell is very good at it – very calm voice, always telling the client how well they are doing, how it's early days, or it's still very raw, or similar, praising them for getting on with life.

Thus, the volunteers soothed the disorderliness and chaos caused by death (Douglas, 1966/2002), not allowing it to overwhelm either them or their clients whose efforts at returning to 'living' they praised. However, re-reading my fieldnote above about Nell, I am struck by my description of Nell as 'good at it' – that is, how I was complicit with the need to keep clients' emotional distress under control. Examining my feelings further, I realised that I had felt uncomfortable both with the disorderliness of death and with confronting the emotions of others. I recognise this as deriving partly from my personality, but also from a Western cultural script which seeks to avoid death. By providing rationales for why the client was feeling sad or low (I am assuming that this is what the client indicated) the volunteers adopted a 'stage' model of grief, 'allowing' clients' feelings of grief if the bereavement was 'recent' as in 'It's early days yet'.

I noted that Gloria and the volunteers considered such cases to be more 'sensitive' than those where the bereavement was less fresh. This was particularly so if the funeral was yet to be held, as demonstrated by three fieldnotes:

Tegan came in [to Gloria's office – she was using a desk in the other office] to get some of the initial contact calls from the folder. She took one, but it was clear that the client was so 'new' that a funeral hadn't been arranged. Gloria said she should find out when it was. She seemed unsure about this and Barbara swapped with her, saying she didn't mind doing it.

Barbara's phone call to this person involved her asking whether the deceased would be buried or cremated (...) when she'd finished, Gloria commented, saying something like 'that sounded heavy going'.

Gloria explained the client notes that she had given Nell, pointing out that two were quite sensitive as the clients had only been recently bereaved – for one, the funeral was still to happen. Gloria explained that one client was the wife of patient who had had MND [motor neurone disease] and had tried to kill himself by refusing to use his oxygen. However, he was still alive the next day and was angry. Eventually he died.

In the first extract, Tegan, who had less experience in the volunteer role than others, clearly felt uncomfortable talking to a client whose relative had died only recently. The period between death and the funeral can be seen as liminal (see Howarth, 1996). The unburied body is 'matter out of place' and therefore potentially contaminating until it is made safe, both literally, through internment or cremation (Howarth, 1996), and socially, by the funeral ritual (Douglas, 1966/2002). The second extract was only one of two cases I heard where explicit reference was made to the disposal of the relative's body. The other concerned the issue of a client who felt uncomfortable splitting their relative's ashes between members of the family. Gloria's comment, *'That sounds heavy going'*, acknowledged that the conversation was a potential drain on Barbara's emotional resilience and gave Barbara a chance to 'offload'. Unfortunately, I did not record Barbara's response. The case of the patient with MND generated a 'sensitive' case because here death was not well controlled, and thus likely to be a 'bad death' (DeVecchio Good et al., 2004). The extracts also show how the more sensitive cases were given to the more experienced volunteers. 'Difficult' cases were also taken by Gloria herself:

Gloria had just finished with a difficult client, she told me. She said that some clients were unhappy but wanted to move forward, but this client didn't seem to want to be happy. She didn't want to stop having contact but it was difficult if the client didn't 'improve'. She would like to stop sessions with this client but she always worried that someone would commit suicide if they stopped having contact prematurely. I had overheard some of her conversation with the client – she asked the client if she was taking her antidepressants.

In this fieldnote, as in the case of the new Coffee Time client above, it seemed that the client was expected to 'collude' with the process of being brought back to 'living' regardless of how they are actually feeling. In Chapter 2 I discussed how the hospice movement aims to produce a 'good death'. Extrapolating from this concept I argue that in the same way as a 'bad' death is a death which is out of control, such as suicide (Howarth, 2007), a 'bad bereavement' is one which does not end in 'appropriate' resolution. Gloria's client, above, was therefore not following the usual process, producing 'disorder' and potentially a 'bad death' if they took their own life.

Of course, some clients were positive in the face of their loss:

Tegan told me about a client she had rung who said she was 'having a ball' [since her husband died] as 'he had been very controlling and wouldn't let her have fast food.... Don't get me wrong, I

loved him...'. Tegan said she had laughed with the client. She mentioned this again when Gloria came back.

I thought Tegan seemed relieved that the client was 'happy' and I wondered whether she was trying to offset the 'emotional labour' involved in her role, a concept I introduced in Chapter 5 (section 5.6). It refers to the work involved in dealing with others' emotions which can be demanding and potentially exhausting (James, 1989). Although all the volunteer roles involved some aspect of emotional labour, it was most apparent in the bereavement team volunteer role, particularly during Telephone Support: as the 'script' above said, 'whatever you're feeling' [emphasis added]. Emotional labour is particularly noted in caring roles (James, 1989, 1992). Therefore, support for carers (however defined) is important to help them cope with the 'painfulness of empathy' (Relf, 1998, p. 63).

Furthermore, it is common practice for people working as counsellors, for example, to receive supervision themselves in order to work through any emotional issues that their work has raised (British Association for Counselling and Psychotherapy <https://www.bacp.co.uk/membership/supervision/> accessed 28/1/19). Hopkinson (2002) identified that at shift handover sessions nurses who care for dying people cope with the emotional labour involved by 'facilitating the sharing of thoughts and feelings'. Hospice staff also recognised the importance of caring for their own emotional health. As I described in Chapter 5, day hospice staff spent a weekend away together for this purpose. Gloria, in her comment above about the view from the office window being her 'sanity' also references this need (drawing on the restorative power of nature, an important plank in hospice ideology). On one occasion I overheard a conversation between her and Lily who worked with bereaved children. I arrived to sit in on a telephone support session, when Lily, who shared an office with Gloria, was still at her desk. She said, '*I have strategies to wash it away*' [meaning to forget about work] '*but you often think about what you have to do the next day*'. The volunteers also recognised the emotional demands of their role:

When we were starting to pack up, I was standing behind Mona and Nell who were still sitting at their desks – I was collecting mugs – Mona said to Nell, 'I don't get as involved as I thought I would'. Nell replied, 'You have to distance yourself. You can't take it home. But some of them you think about'.

Earlier in that session Nell had mentioned that she had been speaking to a woman aged 93 whose daughter, her carer, had died. I wondered whether this example of a 'disorderly' death (Walter, 1991; Komaromy & Hockey, 2001), where someone had died while a relative of a previous generation was still living, had 'disturbed' Nell in some way.

Since a common motivation for becoming a hospice volunteer is the death of a relative who used hospice care (Claxton-Oldfield et al., 2013), both hospices ruled that new volunteers could not be recently bereaved. Flora House's volunteer policy document defined a wait-time of two years, while at Daisy Hospice the period was one year, extended to two years for bereavement volunteers. This showed the importance placed on the volunteers being emotionally stable themselves, although there is evidence that such a requirement may not be necessary provided volunteers have the necessary support (Andersson & Ohlen, 2005). Indeed, expressing a time period shows support for a stage model in which grief follows a temporal model towards resolution. I came across only one case of a volunteer who was bereaved while being involved at the hospice – Gaye, a general volunteer in the inpatient unit at Daisy Hospice. She was not required to resign and returned to her role after missing a shift.

In this section I have shown how the volunteers supported 'living' in the Telephone Support sessions and how the 'sensitivity' of a case depended on the recency of the associated death. The more 'sensitive' cases were handled by the more experienced volunteers or by Gloria herself. I have also discussed the issue of 'emotional labour' which was particularly relevant to this group of volunteers. Of all the volunteer groups I followed, the bereavement team received the most training and supervision although they had no contact with dying patients. I discuss this in the next section in order to explore further the importance of experience in dealing with death.

8.5 Death is for experts

As I described above the importance of volunteers being trained was highlighted by being clearly stated in the small print on the written information given to clients. Gloria reiterated the necessity of training for bereavement team volunteers at the supervision session I attended:

The session started with Gloria explaining what they would be doing, then gave 'notices'. The main one was about the memorial events. Liam asked if partners could come, and Gloria said she didn't think so. Liam then said that his wife had come last year, and they talked for a while before realising that his wife had helped with directing traffic, which members of the public were invited

to help with, while anything to do with the bereavement team [that is, contact with bereaved relatives], was limited to trained volunteers only.

As stated above Gloria told me that she had begun involving volunteers in bereavement work around two years previously. She had run a training course for potential volunteers one evening a week for ten weeks, which she planned to re-run every eighteen months or so to recruit new volunteers. This was partly to increase the size of the team in order to offer services to more people and partly to deal with attrition. She explained that the course covered general grief skills (I did not ask her what she meant by these), facing one's own losses, learning about loss and the stages of grief: 'early, mid, endings'. She had also included telephone support scenarios. I asked about which grief models she used, and she indicated Shorts, Worden, and Kubler-Ross, as well as covering bereavement practice in other religions and cultures, hospice policies and safeguarding, which was a statutory requirement.

The training given to volunteers in the bereavement team contrasted with that given to other volunteers, who received on-the-job training to learn the specific tasks involved in their roles but nothing that focused on patients' emotional needs. Daisy Hospice ran a session attended by all new volunteers where the hospice and its work were described, together with an overview of the 'patient journey'. This ran only once during the time I observed. I was unable to attend, but a volunteer showed me the programme.

As well as being trained, bereavement team volunteers were also required to attend supervision sessions approximately monthly. From my fieldnotes of a Coffee Time session:

Frances asked [Gloria] if she could come as well [to the lunchtime supervision session] as the supervision session she was meant to be attending was now inconvenient as she had to pick up her son from the airport (...) Gloria said, 'That's fine. It's people who don't come to supervision that are the problem'.

Gloria's comment echoes the occasions above when she checked up on the volunteers at Coffee Time, implying that volunteers needed constant surveillance to ensure that they did not, in her words, 'revert to being volunteers'. Volunteer Iris, who was a retired nurse, told me that she had never had so much supervision, more than when she was nursing. Her comment suggested that a high level of supervision was required for the volunteers because they were not 'professionals'. This was also apparent in other monitoring Gloria undertook of volunteer activities. Regarding the

one-to-one sessions volunteers undertook with clients, she told me that she has *'to trust that they are doing what they should be doing'* and that she does *'some checking but had one volunteer who she found out had been having tea once a week with a client for a year!'*

I argue that Gloria was performing 'demarcation work' (van Bochove et al., 2018) checking up on the volunteers to ensure that they performed their role correctly. In other words, it could be suggested that she saw them as unreliable, one of van Bochove et al.'s (2018) 'boundary markers' (discussed in Chapter 2) distinguishing volunteers from professionals. Gloria had also indicated that she 'directed' the volunteers in the Telephone Support sessions:

She said the volunteers I'd seen tonight were very competent and that sometimes she had to direct them more.

I argue further that Gloria reinforced the volunteer-professional boundary by clearly positioning the volunteers as *non*-professionals when she reiterated several times during my observations that, when volunteers undertook one-to-one sessions, they were not 'counsellors'. For example, at the supervision session I attended:

At one point Mona referred to what they did [the one-to-one sessions] as counselling, and Gloria corrected her saying, 'You aren't a counsellor'.

In my extended conversation with Gloria she told me that:

The one-to-ones [i.e., one-to-one sessions between volunteers and clients] are not counselling sessions as the volunteers aren't professionally qualified, although they use counselling skills.

Undertaking one-to-one sessions meant that the volunteers had to deal directly with clients' emotions. These sessions were therefore the most closely 'guarded' activity. Before volunteers could undertake them, Gloria had to consider them to be 'ready' and she explicitly stated this at one Coffee Time session. This occurred in the course of conversation among the volunteers when volunteer Ursula mentioned that she kept a tee-shirt in her linen basket belonging to a family member (she said the name assuming the others knew who this was) which she had never washed as she liked to sniff it from time to time. Neither Gloria nor the other volunteers picked up the thread of conversation. I did not ask the details, but this incident makes most sense if the tee-shirt had belonged to someone who had died. I argue that by allowing death into the session,

even out of earshot of the clients, Ursula had breached the life-death boundary which was being so carefully managed. Shortly afterwards Gloria whispered to me that she did not think Ursula was suitable to undertake one-to-one sessions.

I suggest that the discrepancy in the training and supervision given to bereavement volunteers compared with others was partly to cope with the 'emotional labour' involved in their roles. However, there may be an additional explanation. Gloria's colleague, Lily, shared Gloria's office and, once a month, stayed late on the same evening as Telephone Support to run supervision for bereavement volunteers involved in supporting children. On this occasion I arrived before she left to run the session. She and Gloria were discussing the introduction of new paperwork:

... Lily said 'We're offering a professional service, we have to do it professionally. We're asking our volunteers to complete more forms from the New Year'.

Thus, a 'professional' service requires 'professional' standards which therefore necessitate training and subsequent monitoring. This shows how death must be handled by experts, that is, by people who are 'trained' and 'professional'. However, elsewhere I have shown that there was tension between 'volunteer' and 'professional' (Ganesh & McAllum, 2012). Gloria's comment above about undertaking a monitoring role to '*stop them from reverting to volunteers*' contrasted with her undertaking 'demarcation work' (van Bochove et al., 2018) to position the volunteers as non-professionals, for example, in the comments above about the volunteers not being counsellors. As in Chapter 6, I argue that the issue here is that 'volunteer' is being discursively positioned as a leisure activity. I discuss this further in Chapter 9.

In this section I have shown how my data illustrate that training and supervision were important in the bereavement volunteer role, suggesting that this was partly because of the importance of death being handled by experts. Further, my data show how Gloria performed 'demarcation work' by marking out the professionalised territory of 'counselling'. However, she also performed 'welcoming' work (van Bochove et al., 2018) by involving volunteers in the skilled tasks of dealing with 'sensitive' cases and in one-to-one sessions. Next, I discuss further the 'welcoming' aspect of Gloria's role, illustrating how she relied on the volunteers to run the service and how ultimately the volunteers retained autonomy.

8.6 Volunteers: we can't do without them

Compared with volunteer roles in other hospice settings, the volunteer-staff ratio was the highest in the bereavement team, with one member of staff and up to five volunteers per session. Gloria therefore relied on them to be able to run the bereavement service. She told me in an extended conversation, *'We can't do without them'* and that she would like to increase volunteer numbers to *'50 to run properly'* to provide additional services, such as befriending, more pre-bereavement work and a regular monthly event, such as an outing. On many occasions she told me how *'fantastic'* the volunteers were, and she was anxious that I was not seeing them *'in action'* by attending only Coffee Time (although I was also sitting in on Telephone Support at the time).

From my fieldnotes:

She said it was a shame I couldn't sit in on the one-to-ones as I would then see what volunteers are really doing, and I said that it wouldn't be appropriate and she agreed.

She encouraged me to attend the memorial services, *'You'd see them at their best'* by which she meant that I would directly observe the volunteers interacting with bereaved relatives. Gloria's praise for the volunteers contrasted with the *'demarcation work'* she undertook to establish and maintain the volunteer-professional boundary and with the effort she made to ensure that there were enough volunteers supporting each session. In some Coffee Time sessions and the supervision session I observed, Gloria asked the volunteers to fill in the rotas. Some sessions were more popular with the volunteers than others:

[From supervision session] Gloria handed round rotas for Coffee Time, Telephone Support and Pub Meet, asking them to sign up, saying she liked to have three volunteers at Coffee Time if possible. The Pub Meet rota was filled up until July – she said that was because it only happened once a month and it was popular with volunteers.

At the time I observed the memorial services were due to take place in around a month's time. Both took place on a Saturday, the first in the afternoon followed by the second in the early evening. Gloria had not managed to fill up the rotas, especially for the later service:

Gloria asked Barbara if she could do the second memorial service as she didn't have enough volunteers for this.

I noticed that the volunteers enjoyed a great deal of flexibility in altering the rotas at short notice to suit their personal lives, illustrated by the following fieldnotes:

Dana [administration volunteer at Telephone Support] called through to apologise for not coming the week before but they had decided to go away at short notice. Gloria said it wasn't a problem.

While Gloria was with her client, Frances came through to ask Dana where the Coffee Time rota was as there was a day she couldn't do which she thought she'd signed up for. She found it on the notice board above Gloria's desk, and made an amendment.

[At Telephone Support] Barbara [said to Gloria] wanted to change a date she had agreed to do.

The volunteers liked to retain their flexibility:

Ursula told me she didn't like to book [herself into the rotas] too far in advance in case things came up.

The flexibility of the volunteer role was also important for volunteers in other settings. However, the bereavement team volunteers seemed to take most advantage of it, with those in other settings, particularly inpatient unit general and care assistant volunteers, giving plenty of notice of any shifts they could not undertake. While I am not suggesting that the bereavement team volunteers were not committed to their roles, I argue that they may have enjoyed increased autonomy compared with volunteers in other settings because of the high volunteer-staff ratio per shift. This raises issues about the nature of volunteering, in particular the role of flexibility, which has been identified as a core value (for example, Guirguis-Younger et al., 2005). I discuss these, along with the special place of volunteering in the hospice movement, in Chapter 9.

8.7 Summary

I began my exploration of the role of the bereavement team volunteers by examining the written information produced by the hospice which formed the 'script' for the sessions. This established the focus of the team's activities as helping clients to move forwards and re-join 'living'. The volunteer role was positioned as supporting clients in dealing with potentially chaotic emotions, helping to sustain 'living' and move bereaved relatives from death back to life.

At the socially oriented Coffee Time sessions I showed how the volunteers acted as 'hosts', part of which was to monitor the life-death boundary to ensure that death did not intrude. Further, at Telephone Support they helped to ensure clients were moving towards 'living' smoothing the potential disorderliness and chaos caused by death. However, death itself was for experts, so the more 'difficult' or 'sensitive' clients were passed to the more experienced volunteers or taken by staff. In comparison with volunteers in other settings, these volunteers received considerable training and supervision, and had more autonomy, having their own clients and a range of activities with which to be involved. In any one session they outnumbered staff, unlike other volunteer groups. However, the bereavement volunteers had no contact with patients, so were not in direct contact with death and dying. This raises an interesting contradiction since those involved with patients would be expected to have the most training and supervision. However, as I have shown, death is professionalised territory. Therefore, volunteers with direct contact with death were kept from it by being positioned in unskilled roles. This also supports my findings in Chapter 7 showing how 'difficult' some of the 'professional' volunteers found it to be accepted.

Chapter 9. Discussion and conclusions

In this final chapter I summarise my research and its findings. Since the thesis has shown the importance of the life-death boundary in explaining the volunteer role, I show how I reached this conclusion and offer a theoretical explanation, drawing on the seminal work of Douglas (1966/2002) on boundaries and also on Froggatt's (1997) ideas about the hospice as a liminal place which I outlined in Chapter 2. I also suggest theoretical explanations which might account for other aspects of my findings, in particular why the 'unpaid' status of volunteers appears to make such a significant difference to their role. I provide some methodological reflections before considering the strengths, weaknesses and contribution to knowledge of this thesis. I offer suggestions for further research and, finally, consider possible implications for practice.

9.1 Summary of the research process and findings

I began this thesis by describing my experience as a volunteer and how this led me to realise that the label 'volunteer' had a social meaning that appeared to have nothing to do with the characteristics of the individuals filling the role. This matter was raised again much later when I became involved in a research project about hospice volunteers, part of which examined existing literature on how the volunteer role was 'understood' by those concerned (Burbeck, Candy, et al., 2014). This revealed tensions in the role, including whether volunteers provided a different kind of care to paid staff or whether they simply helped to stretch funding, that is, whether they were '*complementary or substitutive*' (Sevigny, 2010, p. 743). The aim of my thesis was therefore to uncover how the hospice volunteer role was constructed. To support my research journey, I asked five sub-questions based on issues drawn from the literature:

- 1) Is the volunteer role distinct from that of (paid) staff?
- 2) How does the relationship between staff and volunteers generate and sustain the role?
- 3) How does the hospice as an institution construct the role?
- 4) How does the context of death and dying shape the role?
- 5) How can this understanding of the volunteer role inform practice?

I took an ethnographic approach in order to explore at first hand the volunteers' world in its everyday context. As I stated in Chapter 3 this involved adopting an unstructured approach to

data collection and allowing the data to lead the research in directions not necessarily envisaged at the start (Hammersley & Atkinson, 2007). Appendix I shows how the first four of my research questions were answered in each data chapter (Chapters 4 to 8) and how the main theme of 'boundaries' emerged. (I consider the fifth question below in section 9.8.)

In Chapter 2 I set the scene by explaining how a volunteering ethic was at the heart of the original hospice ideology and that volunteers promoted the 'alternative' nature of the nascent hospice movement. They were not members of a professional group so did not represent the institutionalism the new movement was aiming to replace. I discussed how the hospice movement had originally set out to *de*-medicalise death and dying but, as the movement matured care became *re*-medicalised and, importantly, professionalised. This was partly through the necessity to recruit staff from the NHS which meant that the medical model of care came to dominate the social structure of the hospice. It is therefore within the frame of the medical model of end-of-life care that I have argued that my data show how volunteers became, what Douglas (1966/2002) calls, 'matter out of place', within the professionalised territory of death and dying.

Other than Chapter 4 each chapter focused on a different group of volunteers and demonstrated a clear distinction between them and paid staff. For example, Chapter 5 showed how the volunteer role both contrasted with, and complemented, staff's role, while in Chapter 6 I argued that volunteers were isolated from staff. In Chapter 7 I showed strategies which I contended were employed to treat 'professional' volunteers more directly as 'matter out of place'. Next, in Chapter 8 I focused on staff's 'demarcation' strategies which positioned volunteers as *un*-professional. The hospice ideology of 'living until you die' helped to construct the 'general' volunteer roles through hospitality practices. However, it was clear that the life-death boundary was particularly carefully managed and therefore highly significant in explaining the volunteer role.

Beginning with the importance of physical boundaries in maintaining the life-death boundary, in Chapter 4 I used Lefevbre's (1991) theory of space and Goffman's (1959/1990) theory of regions to explore the hospice buildings, spaces and materiality. How these spaces were presented and used both symbolically and literally reinforced how different roles could be enacted. The analysis established how the hospice as a heterotopic space 'protected' the life-death boundary and how the volunteer role was positioned as inferior to that of staff, so that dealing directly with death required 'professional' status.

Douglas' notion of boundaries helped me to consider the symbolic dimensions of death and dying in relation to the role of volunteers, and Lefebvre and Goffman provided theoretical explanations for how the life-death boundary was 'protected'. However, these theoretical explanations did not fully explain the ways in which the volunteer role in relation to this boundary varied in the different settings in which I researched, notably the way this boundary seemed to 'protect' patients who were clinically closer to death. Therefore, to understand this disparity, I drew on Hockey's (1990) construction of living and dying within the hospice movement as a 'biological continuum' (p. 155). Hockey identified the processual/temporal aspect of hospice ideology as a journey, presenting the patient/relative's route through the different settings as from 'living' to 'dying' through death and back to 'living'. By using setting as a proxy for patient clinical status (or client in the case of bereavement care), I argued that the volunteer role became most bounded when the patient was 'closest' to death, that is, in the inpatient unit.

In the day hospice and in bereavement care, where the focus was on patient rehabilitation rather than on medical care *per se*, volunteers had more autonomy and undertook their roles alongside staff with a fair degree of integration. However, in the clinical environment of the inpatient unit where the social structure reflected that of the medical model, the role was placed outside the professional boundary of care. Thus, I suggest that the construction of the volunteer role was based on how hospice ideology constructed the patient/client's clinical status in each setting. Where the patient/client was 'living' and death was not literally (or, at least, legitimately) present (day hospice and bereavement care), the role was relatively autonomous compared with that in the inpatient unit. Here, where death *was* literally present, the production of 'living' was harder to achieve, and the volunteer role became most constrained.

These theories helped me to explain what was happening around death and dying, but to explore the idea of 'living until you die' and how this was produced in each setting, I turned to Goffman's interactionist ideas about 'dramaturgy' and impression management which I described in Chapter 2. Goffman is concerned with the social meaning of actions, in particular of groups of people 'working' together. I showed how the hospice 'scripted' 'living' through leaflets and other material given to patients. Using the concept of hospitality (King, 1995) and Douglas' (1975) notions about the use of food practices in maintaining order, I highlighted how the 'general' volunteers' 'host' role in the day hospice and inpatient unit located them within the production of 'living' and away from the life-death boundary, which was managed and approached mainly by 'trained' staff.

I noted how actor groups were agents in constructing role boundaries and to explore these in more depth, within the wider theoretical concepts discussed above, I drew on interpretations of organisational roles, in particular van Bochove et al.'s (2018) extension of Gieryn's (1983) concept of 'boundary work' into 'demarcation' and 'welcoming' work. For example, bereavement team staff undertook boundary work to position themselves as 'professionals' locating volunteers as non-professional. Conversely, staff performed 'welcoming work' by locating volunteers in the bereavement team in the first place. This presented an interesting contradiction which I explore below. Furthermore, staff emphasised how volunteers were *un*-professional by drawing on a discourse of volunteering as a middle-class leisure activity, for example, in Chapter 7. I argue that doing so legitimised the role of paid staff in the professional management of death and dying while marginalising that of volunteers.

Before considering reasons for the problematic nature of volunteers' unpaid status, I return to Douglas' (1966/2002) ideas about classificatory boundaries and to Froggatt's (1997) ideas about hospice as a liminal place to address *why* death and dying might be professionalised territory.

9.2 The professionalisation of the life-death boundary

Douglas (1966/2002) highlights the culturally symbolic importance of classificatory boundaries in defining clean and unclean 'matter'. She argues that defilement by 'unclean' matter threatens the structure of society and must be 'dealt' with to maintain 'order'. Death represents a fracturing of society since the separation of life from death is the most fundamental classification of all. Viewed through the theoretical lens of Douglas' ideas, the careful management of the life-death boundary that I observed was not surprising since the main objective of the hospice movement is the production of a 'good death' (Hart et al., 1998). Arguably, part of this involves avoiding the chaos caused by the messiness of death as discussed in Chapter 2.

Also in Chapter 2 I described how the hospice can be considered a liminal place (Froggatt, 1997). The patients, as *liminars*, are 'betwixt-and-between' (Turner, 1967, p. 71) two domains or statuses: life and death. They are thus ambiguous and potentially unstable. To clarify why this state meant that volunteers were excluded the closer their role came to the life-death boundary, I drew on Van Gennep's (1960) *rites de passage* model which emphasises the social function of ritual which, as Douglas (1966/2002) suggests, makes potentially unsafe things safe. Van Gennep (1960) observed that tribal elders, as masters of ceremony, supervised those who were experiencing liminality. This concept of a 'ritual leader' is used by Hallstein (1992, p. 247) to

understand the role of hospice chaplains in helping patients 'towards transformation' (p. 247). I therefore argue that since it is broadly the case that society allocates authority to the hospice to ensure that patients move 'safely' from life to death, the notion of masters of ceremony is useful in understanding how entrusting the care of dying people to 'professional' hands fulfils the ritual of caring for dying people.

My data showed that the nearer the volunteer role became to this 'professionalised' territory of death and dying, the more bounded the role became. In Chapter 4 I presented data which suggested that staff were concerned that volunteers could take over paid jobs, a point already noted in the literature as I discussed in Chapter 2. In Chapter 5 I suggested that volunteers may be considered to be 'uncontrollable' because they did not have a contract in the same way as paid staff (section 5.4.2). I suggest that the various boundaries I identified in my data constraining the role within the different settings were strategies to ensure that volunteers were 'kept in their place'. Within the hospice social structure, volunteers were not 'professional' and, as Douglas (1966/2002) might argue, therefore not equipped to manage the final stages of dying.

However, while the professionalisation of death and dying highlights the cultural meaning of death in Western societies, that is, that it must be handled by experts, it does not explain why volunteers are excluded from this category simply because they are unpaid. I now discuss three possibilities. First, are volunteers liminal within the hospice hierarchy and therefore not considered 'part of the team'? Second, is their exclusion a result of the operation of discursive strategies positioning them as *un*-professional? Third, is it because the construction of 'work' excludes volunteering?

9.3 Is the hospice volunteer liminal?

My data show that volunteers were marginalised outside the professional boundary of care (for example, in Chapter 6). Since marginality is a feature of liminality (Turner, 1969/1974), this raises the question of whether their role is liminal. This has been suggested by Vanderstichelen et al. (2018) and, as I discussed in Chapter 2, other researchers have described hospice volunteers as filling a 'middle ground' between professional care and family care (for example, Field-Richards & Arthur, 2012; Sevigny et al., 2010). Several times while working on my data interpretation I considered the possible liminality of the volunteer role. Each consideration was based on an anthropological reading of Turner's (1969/1974) development of van Gennep's (1960/1977) *rites*

de passage model which focuses on status change as a core feature. This reading led me to conclude that the volunteer role itself was not liminal given that the role did not form a step between one status and another. If the focus of my research had been on the individual experience or identity construction of volunteers, I could have argued that volunteering was a liminal experience. An example might have been volunteering as a stage towards gaining a place at medical school.

However, I still would not have shown that the role itself was liminal, just that an individual volunteer was in a state of liminality within the frame of their personal life story. However, Vanderstichelen et al. (2018) describe volunteers as occupying the liminal space 'betwixt and between' staff and family members because volunteers provide care which includes aspects of that given by both groups. This broader use of liminality as a way of visualising the volunteer role as hybrid, thus capturing the ambiguity present, also appears in other organisational literature. Here, the processual aspect of Turner's (for example, 1969/1974) anthropological focus (Thomassen, 2009) is omitted and liminality is used metaphorically as a way of conceptualising a state where the liminal personae are not one thing or another, for example, management consultants (Czarniawska & Mazza, 2003; Sturdy, Schwarz, & Spicer, 2006) and temporary workers (Garsten, 1999).

Within this interpretation of liminality, the concept can help to explain the ambiguity and lack of structure experienced by some individual volunteers within my data. According to Thomassen (2009) 'liminality is unstructure' (p. 23) so, in a given moment, there are no fixed points and 'betwixt and between' becomes a state of 'formless reality' (p. 23). My data showed that this occurred when the boundaries of a role were unclear or the volunteers experienced lack of status. Examples included Dana, the volunteer administrative assistant in the bereavement team who described herself as a 'nobody' when discussing the fact that she did not have her own password for the hospice computer system (see Chapter 8). Melissa, the volunteer art therapist in the day hospice, also experienced significant lack of status and ambiguity which led her to become very unhappy (Chapter 7). However, these are examples of individuals experiencing liminality within their role. It does not necessarily follow that the volunteer role itself is liminal.

Further exploration of organisational literature showed how Garsten (1999) employs the concept of liminality to explain the role of temporary workers. These are 'betwixt and between' conventional positions within an organisation's structure and are thus 'liberated from the social structures that define the experience of regular employment' (p. 607). The first of these aspects

of the temporary worker role, that it is 'interstructural' (p. 603), does not apply to hospice volunteers whose roles were part of the organisational structure of the hospice, being defined by 'job' descriptions and subject to specific volunteer policies (see Chapter 5, section 5.3). However, the idea of liberation from social structures is relevant to the hospice volunteers I observed. For example, neither volunteers in 'general' nor those in care assistant roles in the inpatient units took part in the handover ritual at the beginning of their shifts (See Chapters 6 and 7) which I argue was a key 'structural obligation' for staff. In addition to a lack of organisational responsibility, *liminars* have no authority over other people, a feature of the 'general' volunteer roles I followed for whom Turner's argument about novices is relevant:

The novices are, in fact, temporarily undefined, beyond the normative social structure. This weakens them, since they have no rights over others. But it also liberates them from structural obligations (1967, p. 59).

As Garsten argues, freedom from institutional obligations brings flexibility alongside marginality (1999, p. 615). I found a similar duality of experience for hospice volunteers. Flexibility was seen in a lack of contractual ties which volunteers 'enjoyed', for example, in giving them the ability to take time off from volunteering relatively freely. Marginalisation was apparent in the subordination of the role within the social hierarchy of the hospice.

In sum, I have shown here how some aspects of liminality can aid the understanding of the volunteer role, in particular the experience of ambiguity of some individuals and the freedom from the structural constraints of paid staff roles. However, the role is part of the hospice organisational structure so the theoretical lens of liminality can offer only a partial explanation. My data also showed how hospice staff and volunteers drew on various discursive strategies of volunteering, for example, as a leisure activity or as volunteering as 'helping' (Chapter 7) positioning volunteers outside the professional boundary of care.

Volunteers whose roles directly overlapped with those of staff, notably the volunteer care assistants, were particularly problematic and 'professional' was defined, not by the skills a person possessed, but by their employment status. From this I argue that discursive strategies relating to 'professional' are key in constructing the volunteer role. I now consider the role of such discursive strategies in the production of the hospice volunteer.

9.4 Discursive strategies

The sociologist Taylor (2005) argues that ‘volunteer’ is constructed in opposition to paid work and that this originated with Victorian middle-class women offering unpaid labour in voluntary hospitals. Thus, ‘volunteer’ became associated with people who did not need to work for economic reasons, but rather were doing ‘good works’. I suggest that my data show this construction was to some extent still in evidence in the hospice, helping to maintain the position of volunteers as outsiders. Furthermore, Taylor (2005) suggests that the title ‘volunteer’ was associated only with low status ‘helper’ roles whereas higher status unpaid roles were not. This can be seen today – for example, magistrates are volunteers as are many hospice trustees.

Although there are no data on the socioeconomic status of contemporary hospice volunteers in the UK, the majority are women and are over 60 years of age (Burbeck, Low, et al., 2014 [unpublished data]; IVR, 2003; Morris, Payne, Ockenden, & Hill, 2017). (There are exceptions. For example, St Christopher’s Hospice, London, where the demographic profile of volunteers more closely matches that of the local community (Hartley, 2013)). The hospice movement is aware of the need to improve the diversity of volunteers, not least because societal and demographic changes mean that, while demand for volunteers from all types of organisation may have risen, the pool of potential volunteers may have shrunk for economic reasons or because of family caring responsibilities (Saxton, Harrison, & Guild, 2015). During my fieldwork I met many volunteers who did not fit the traditional demographic model, for example, Katy at Flora House (see Chapter 6).

A further discursive resource used to position volunteers concerned the construction of ‘volunteer’ in relation to ‘professional’. Van Bochove et al. (2018) found that ‘boundary work’ (Gieryn, 1983) undertaken between professionals (defined as paid workers) and volunteers positioned volunteers as ‘unskilled, unauthoritative and unreliable’ (p. 8). In Chapter 7 I highlighted two examples of this, one where a volunteer positioned herself as lacking authority in comparison to a staff member and one where staff were described as seeing volunteers as unreliable. In addition, most of the volunteers I followed performed unskilled manual tasks.

The term ‘professional’ is used in the literature to describe occupational groups, such as medicine and nursing which require prescribed training to gain membership (Twigg, 1989). It is also used to refer to paid work as opposed to unpaid work. (It is in this latter sense that I distinguished ‘general’ volunteers from those offering their professional skills in this thesis.) I consider that for

hospice volunteers 'professional' in the sense of occupational group has become conflated with 'professional' in the sense of someone being paid to do a job. In other words, professionalism is used 'as a discursive and normative referent in the organization [sic] of volunteers' practices and identities' (Ganesh & McAllum, 2012, p. 153) so that 'volunteer' is defined in opposition to 'professional'. This suggests that volunteers are not so 'good' as paid staff, that they have lower status, cannot be 'trusted' and are not reliable in the same way as a 'professional'. This may explain why I met so few volunteers in 'professional' roles, and why some of those I met, such as the complementary therapists, worked so hard to maintain a 'professional' boundary (see Chapter 7).

However, the contradiction remains between volunteers requiring training and supervision to provide a 'professional' service (See Chapter 8) and the hospice movement valuing volunteers for not being professionals and providing a different kind of care to that of paid staff (Help the Hospices, 2012). I discuss volunteering in the hospice movement more generally in section 9.8 below, but first consider whether another way forward is to explore the relationship between volunteering and 'work'.

9.5 Is volunteering 'work'?

Grint (1991) has argued that work is socially constructed insofar as it is discursively contrasted with non-work and with leisure (1991). In Chapter 7 I described the incident when volunteer care assistant Lucy 'negotiated' a task with a paid staff member. A healthcare assistant explained to Lucy, 'I'm paid to do it', thus articulating a simple categorisation of staff and volunteer based on pay status. Despite feminist critiques which have seen women's unpaid, informal work in the home being recast as work (Oakley, 1974), Taylor (2004) argues that the conceptual boundaries of 'work' within sociology have not shifted from a simple paid/unpaid dichotomy. She suggests that a more nuanced framework more accurately reflects the complexity of everyday life. By showing how the domains of paid/unpaid, public/private and formal/informal intersected within the lives of her study participants, she re-defines work as 'an activity (...) [which] involves the provision of a service to others or the production of goods for the consumption of others' regardless of whether it is paid or not (p. 18). This definition provides a theoretical basis for extending the conceptual boundaries of 'work' to include volunteering. For example, one of her interviewees had both a paid job and an unpaid role in the voluntary sector. Interview data revealed that he viewed his paid work as supporting his unpaid role, which he considered more important.

Taylor's framework allows for individual differences between volunteers about the meaning of their voluntary work and this is reflected in my own data. For some volunteers, like Lance in Chapter 6, a volunteer role was a stepping stone to a medical career, while for others, like Betty and Deidre, it was a way of being useful in society and of spending their free time constructively. While volunteer motivation has not been a focus of this study (and is extensively researched elsewhere, for example, Claxton-Oldfield et al., 2013), it is helpful to remember that a one-size-fits-all approach to volunteering is not appropriate.

Viewing paid work and volunteering as categories of work may help to dispel notions of volunteers as unprofessional, although a balance needs to be struck between this and avoiding 'professionalising' the volunteer role and so losing the 'specialness' of volunteers.

So far in this chapter, I have reviewed and discussed my findings about the importance of the life-death boundary. I have showed how understanding the hospice as a liminal place necessitating the involvement of 'ritual experts' may help to explain why death and dying is professionalised terrain. I then examined why being unpaid excludes volunteers from this territory. I considered whether the role is liminal within the hospice and concluded that this may be so only within a metaphorical understanding of liminality used in some organisational role research. Drawing on Ganesh and McAllum's (2012) view of 'volunteer' as constructed in tension with 'professional', I looked at the discursive strategies used by staff and found that these help to unpick why volunteers are seen as un-professional. Finally, I considered the extent to which volunteering can be classed as 'work' finding that the construction of 'work' as 'professional' is in effect a further discursive strategy which excludes volunteers.

Having summarised my findings and suggested alternative explanations, I return to the issues I raised in Chapter 3 about the status of 'thick description' in producing a valid and reliable account.

9.6 Methodological reflections

I took a social constructionist approach to the volunteer role in hospices and adopted an ethnographic approach relying on participant observation as the main data collection method. In Chapter 3 I explained how I planned to use Brewer's (2000) suggestions for reflective practices to establish the legitimacy of the ethnographic text. I now consider how I have followed these guidelines and reflect on their usefulness:

Establishing the wider relevance of the setting and the topic – that is, to consider the extent to which the fieldwork sites and the volunteers I follow are representative of similar settings (p. 53);

Both Flora House and Daisy Hospice were voluntary run, in urban areas and involved volunteers across a range of services in face-to-face roles. These features are typical of other hospices in the UK (Burbeck, Low, et al., 2014). I highlighted differences between the hospices in the thesis, notably between different practices involving volunteers and in the services offered. For example, I described the differences in shift patterns for the ‘general’ volunteers in the inpatient units (Chapter 6) and in the aims of the day hospice sessions that I followed (Chapter 5). The two hospices were in different counties in the south of England, so it could be argued that my findings do not have applicability outside of these areas. However, as far as I am aware, no factors affecting volunteers based purely on location have been reported. In terms of feasibility, researching in a hospice more than an hour’s drive from my home would have been impractical.

Identifying the features of the topic being addressed (and those not being addressed) in order to be explicit about why I chose some aspects to research above others (p. 53);

In Chapter 1 I explained that the research was based on volunteers in face-to-face roles and that I focused on their *role* rather than on characteristics of the volunteers themselves, such as motivation. While this allowed me to emphasise the role and uncover the way that ‘volunteer’ was constructed in the hospice, it meant that I could not explore the volunteers’ individual experiences although, as I pointed out in Chapter 2, there is a growing body of research which covers these. Narrowing the scope of research can help to provide analytic depth.

Identifying my theoretical framework including the broader values and commitments I bring (p. 53);

Although I brought no specific political or religious values or commitments to the study, as I described in Chapter 1, I approached ‘volunteer’ as a social construction, partly because of my personal experience of being a volunteer and partly because of some previous work in which I had been involved. In Chapter 3 I identified my ‘moderate’ social constructionist standpoint and its relationship to an ethnographic approach, notably the issues around the use of ‘thick description’ and the ‘truth’ claims I could make as a result. As Seymour (2007) suggests, ‘thick description’ acquired by looking at a variety of events within a setting can help to reveal the symbolic

meanings behind what is going on and therefore has explanatory power allowing 'inferences to be made that have a wider applicability beyond the context of the study at hand' (p. 212).

Establishing my integrity as a researcher by outlining the grounds on which I am making knowledge claims, including describing specific aspects of the fieldwork (such as time in the field, how access was negotiated, and the extent of rapport developed with respondents); my background in relation to the setting and my experiences during the research, including any constraints; and the strengths and weaknesses of the research design (p. 53);

I explained my methods in Chapter 3 and how my interest in volunteers arose in Chapter 1. I discussed my identity as a researcher, in particular that I was an 'outsider' with limited experience of hospices and with no clinical background. Although I came to see this as a strength, as I explained in Chapter 3, it meant that during the early phases of analysis and writing I tended to focus on issues which, while important as context, were not specifically relevant to volunteers. However, on occasions these 'diversions' provided useful insights into the volunteer role. An example is my analysis of the patient rooms in Chapter 6. I consider the strengths and weaknesses of the research design in section 9.7.

Establishing the authority of the data by outlining any problems that arose during fieldwork; describing how the analytical framework was developed; providing sufficient data extracts for readers to assess the interpretation provided; giving rival explanations and suggesting alternative ways of organising the data; and considering power relations within the research (p. 54);

I discuss problems which arose during fieldwork and the decisions I took in Chapter 3 and, where appropriate, in Chapters 4 through 8. I consider that I have provided sufficient extracts from my fieldnotes and from hospice documents to allow readers to assess my interpretation. I have given alternative explanations where appropriate, although I have not suggested other ways of organising the data. I considered other organisational schemes, such as one based on topics (such as food practices and death and dying), however none focused on volunteers sufficiently to offer the explanatory power which I gained by considering my data by setting. Hockey's (1990) 'continuum' was key in unlocking this aspect of my analysis and, therefore, to my overall findings.

I have touched on the issue of power briefly in Chapter 3 when I compared the gatekeeping process at each fieldwork site. I explained how it was 'easier' at Flora House as I already had an entry into the hospice through my supervisors, and the hospice had previously hosted

researchers. This was not the case at Daisy Hospice, where I found the process of gaining access more difficult. As I stated in Chapter 3, I found the researcher role 'uncomfortable' since my role was not a natural part of the hospice set-up. I found it hard to explain to participants what I was doing. It seemed to participants that I was just 'hanging around'. Gloria, the Bereavement Team Coordinator at Flora House, for example, kept asking me, '*Have you got what you want?*'. I found it hard to explain that I just wanted to watch what was happening and thus navigating the tightrope between self-disclosure and being an objective researcher was always a challenge.

Showing complexity within the data including negative cases, multiple explanations offered by respondents, and the contextual nature of respondents' accounts (p. 54) (Adapted from Brewer, 2000, p. 53-4).

I showed complexity in the data throughout the data chapters, such as the different construction of the volunteer role in each setting. In the present chapter I have provided an account of the process of selecting the appropriate theoretical explanation and considered alternative explanations. In Chapter 6, I give an example where respondents offered different explanations about feeling comfortable when patients were moved after death (section 6.5.2).

Finally, considering Brewer's guidelines helped me to make a claim that my account of volunteers was a 'true' one, although other accounts may be made. As Brewer (2000) points out, it is for the reader to make their judgement. The guidelines cover the major issues which need to be considered in judging the quality of ethnographic work.

9.7 This study's contribution to knowledge, strengths and limitations, and suggestions for further research

While an economic argument has been made for the importance of volunteers to the hospice movement based on growing demand for services in a challenging economic context (Scott et al., 2018), account has not been taken of the social processes when volunteers and paid staff are involved in the same organisational setting. This ethnographic account of the role of volunteers helps to fill this gap. To date, this study is the first to explore, at first hand and in depth, the hospice volunteers' world in its everyday context. Furthermore, this account provides data on volunteers from two hospices in three different hospice settings, which allowed comparison between volunteer roles and which was key in reaching my conclusions.

As I highlighted in Chapter 2 other studies of hospice volunteers used interview or focus group data, and also combined data from volunteers (and others) across different settings. I argue that my approach is a key strength of this study which allowed me, through the various theoretical lenses I employed, to show how volunteers were excluded from the territory of death and dying, particularly within the medical model. In addition, Martin, Nettleton, Buse, Prior & Twigg (2015) call for medical sociologists to pay greater attention to the materiality of buildings used in healthcare. Chapter 4 has therefore addressed this omission about hospices by using ethnographic data to show how hospice ideology is played out through the configuration of buildings, spaces and material culture within an ethnography. I argue that my study makes several unique contributions to the literature.

However, a limitation of this study is that I was able to study bereavement team volunteers at only one hospice. This means that my data are less rich in this setting compared with the other two. Also, apart from volunteer managers and some senior staff, I spoke only to staff who had contact with the volunteers I followed. I did not undertake separate fieldwork sessions with staff. Therefore, their voice is largely absent. To give a more rounded picture, further research could be undertaken specifically with staff to explore their experiences with volunteers. Similarly, the patient voice is absent. Given the hospice movement's view that volunteers provide a different kind of care compared with staff, it would be helpful to understand this somewhat intangible aspect of care from the patient perspective. Gaining ethical permission to conduct research with patients can be difficult, but provided researchers are sensitive to the issues involved (Seymour et al., 2005), the patient voice would be key to improving hospice care.

As I explained in Chapter 3, I chose not to use interviews as a data-gathering method although they are commonly undertaken as part of an ethnographic approach. For example, Fox (1992) compared discourses identified in interviews with fieldnotes from observations to illuminate how surgical practice is socially constructed. Although interviews are an important way of gathering insights into respondents' lived experience, they can also be seen as an unnatural type of conversation through which data are co-constructed between the interviewer and interviewee (Walford, 2007): 'Interviews can inform us of what the person interviewed is prepared to say about a topic in the social context, time, and place of that particular interview' (Walford, 2018, p. 14). Since I was interested in exploring how the volunteer role operated in the real-world context of the hospice, my focus was on what volunteers said and did in their natural everyday setting rather than on what they might say they did (Walshe et al., 2012). Therefore, I felt that observation was the most appropriate method.

However, not undertaking interviews with volunteers meant that I talked to them only as opportunity arose during fieldwork sessions. Being aware that my presence in the field would have some effect, I took care not to introduce topics of conversation beyond what was relevant to what was happening at the time in order to focus on everyday events. I wanted to observe, listen and absorb the world of the volunteer and I was anxious not to produce a 'different' world. Although I garnered many helpful insights with this approach, it meant that I was unable to explore some aspects of the volunteers' experiences in depth, such as about how they perceived their roles and interpreted events around them. For example, as I explained in Chapter 3 (section 3.5.1), despite an extended period in the field I missed volunteers' reactions to the death of a well-known patient on the two occasions this occurred during my fieldwork. Further, I had fewer opportunities for conversation with volunteers whose time was spent mostly 'front stage' with patients, such as in the day hospice, than I had with those who spent more of their time in 'back-stage' spaces as was the case in some inpatient unit roles. Undertaking formal semi-structured interviews with a few volunteers from each setting would have helped to plug these gaps adding richness to the observation data and further helping to triangulate the data.

This is another limitation of this study. However, returning to the field to present the findings of my project at the original fieldwork sites would provide some scope to capture the views of volunteers as well as staff. These opportunities could provide the basis of further research and help to build on the findings of the present work.

A great strength of the hospice movement has been its freedom to innovate without the constraints experienced by statutory services. A manager at Flora House told me that the hospice was shortly to trial a new way of recruiting general volunteers which would move responsibility for recruitment from the volunteer managers to the individual departments (day hospice, inpatient unit, bereavement team). She hoped that volunteers would then be seen as part of the team rather than a separate resource. Volunteer management was not a focus of the present research, but it would be useful to assess the impact of this change on volunteer experience.

A theoretical approach which might offer further insights into the volunteer role would be to consider 'volunteer' as a 'subject position'. This refers to Foucault's notion of the way that social actors are positioned in, and constrained by, a discourse (Redman, 1998). Although I have touched on this idea in identifying discursive practices about volunteers (and different volunteering discourses have been identified within the literature (Ganesh & McAllum (2009)), it

has not been my focus. Further research based on in-depth interviews with volunteers and staff would help to identify such discourse, and findings could inform staff training in their approach to working alongside volunteers.

The gendered nature of hospice work is noteworthy since the majority of volunteers and staff in this study were women. Further, my data show how volunteers were involved in domestic-type work focused on producing hospice as 'home' (Chapters 5 and 6). Such work can be perceived as traditional women's work, as can care work of the type undertaken by volunteer care assistants (Twigg, 2000). Therefore, the gendered nature of volunteers' roles also might be part of the marginalisation of volunteers. While I have not set out directly to provide a feminist critique, research taking this approach might also illuminate the volunteer role.

In Chapter 2 I suggested that the so-called 'distinctiveness' of the role may be a purposively constructed identity on the part of volunteers to legitimise their involvement. I saw little evidence of this kind of identity construction, although research specifically focused on volunteer identity could explore this idea. However, several volunteer managers indicated to me that '*We can't do without them*'.

Although volunteers are involved in paediatric hospice settings to a far lesser extent than in adult settings (Burbeck et al., 2015), it may be worthwhile undertaking a similar study with volunteers in hospices for children and young people. This would help paediatric services avoid the problems encountered by more mature adult services.

9.8 Implications for practice

In Chapter 2 I drew attention to the contradiction in the extant literature between the construction of the volunteer role as '*complementary, not substitutive*' (Seigny, 2010, p. 743) and a more mundane view of volunteers as a way of stretching funding (for example, McKee et al., 2010; Help the Hospices, 2012, p. 6). Pressure between the original ethos of the hospice movement and the marketised healthcare system in which it now operates means that the values of volunteering, such as flexibility, freedom of choice and altruism, are at odds with paid work (Merrell, 2000) leading to disquiet that these values have been compromised (for example, Guirguis-Younger et al., 2005). Demographic and social changes have also altered the nature of volunteering, as I stated above in section 9.4.

The UK Help the Hospices *Commission into the Future of Hospice Care's* 'working paper' on the future of volunteers attempted to address the difficulties (Help the Hospices, 2012). The Commission recognised the different kind of care the volunteers bring: 'volunteers (...) offer a sustained caring connection to people with life shortening illness in all settings and in ways that transcend the purely clinical' (Help the Hospices, 2012, p. 6). However, it is unclear what this means in practice, and how it would be evaluated. The Commission suggested that volunteers should have broader involvement and more significant roles, while acknowledging the need to work within regulatory frameworks. It also called for appropriate training which avoided 'inappropriate professionalisation' but which helped 'the volunteer manage the boundary between the professional approaches to care and their contribution to the team' (Help the Hospices, 2012, p. 7). Similar to the discursive resources discussed above, I argue that this may reproduce the tensions I highlighted in the extant literature in Chapter 2.

My findings highlight the difficulties of combining unpaid and paid personnel in the same setting, particularly within the frame of the medical model, with which I suggested volunteering may be incommensurable. For volunteering to continue to be both a valuable resource and a unique contribution to the care of patients, I suggest that an approach to volunteers could be considered by hospices which makes it clearer that they are part of a team. It may be appropriate for some to attend staff meetings. Terminology could be employed to avoid referring to them as volunteers, for example, by terming them 'team members', 'team support' or 'colleague'. Focus group work with volunteers would help to sound out these suggestions.

Volunteers have a great deal to offer hospices, for example, in terms of life skills (Hoad 1991). Importantly, they also link hospices to their local communities albeit in an 'ad hoc, individualistic way' (Morris et al., 2017, p. 8). Morris et al. (2017) suggest that the 'boundary' position occupied by volunteers between the hospice and its community (p. 8) offers potential for community engagement. This is an important component of the public health model, or 'compassionate community' approach, which is being adopted by some UK palliative care services (Paul & Sallnow, 2013). Such a model is based on the idea that 'health is more than mere absence of illness' and is 'everyone's responsibility' (Kellehear, 2013, p. 1072) and focuses on prevention, harm reduction and early intervention. Examples include strategies to improve health by encouraging healthy eating, exercise, and a reduction in alcohol consumption and smoking. Kellehear (2005) argues that, within palliative care this approach can help to *re-skill* communities which have been *de-skilled* with regard to the care of dying people and their relatives resulting

from the medicalisation and institutionalisation of death and dying. A systematic review of available evidence (Sallnow, Richardson, Murray, & Kellehear, 2016) showed that such approaches improve outcomes, including reducing fatigue for carers, increasing the number of home deaths and improving engagement with palliative care services.

Volunteers are already involved in some initiatives, for example, at the time of my fieldwork, Daisy Hospice, in conjunction with its sister hospice in a nearby town, was recruiting volunteers to a community-based scheme which involved visiting people with life-limiting illness at home. The NPELCP understand that volunteers are vital to such schemes and have called for more to be done to 'recruit, train, value and connect' (p. 34) volunteers in this regard. Hartley (2013) also argues for well trained and supported volunteers in order to meet patient and carer needs. The present study therefore provides further evidence to support these calls.

9.9 Overall conclusions

This thesis highlights the professionalised nature of death and dying, and how the unpaid status of volunteers makes them problematic in this terrain. It shows how the social construction of volunteers might be based on an out-dated formulation of volunteer, for example, as a middle-class woman 'doing good'. Following Ganesh and McAllum's (2012) proposition that the roles of 'volunteer' and 'professional' seem to be held in tension, volunteers are constructed as *un*-professional and thus potentially 'threatening'. Drawing on Douglas (1966/2002), I suggest that volunteers may be 'matter out of place' (p.203) and that volunteering could be incommensurable with the medical model.

Relegating volunteers, particularly those in the inpatient unit, to the periphery of hospice care regardless of the skills they offer contrasts with hospice ideology that volunteers are an integral part of the non-hierarchical multi-disciplinary team. In-depth studies, such as this, can help to reveal the extent to which this is the case, particularly in sensitive areas of care.

References

- Abel, E.K. (1986). The hospice movement: Institutionalizing innovation. *International Journal of Health Services*, 16(1), 71-85.
- Allen, J., & Pryke, M. (1994). The production of service space. *Environment and Planning D: Society and Space*, 12(4), 453-475.
- Andersson, B., & Ohlen, J. (2005). Being a hospice volunteer. *Palliative Medicine*, 19(8), 602-609.
- Ardener, S. (1981). Ground rules and social maps for women: An introduction. In Ardener, S. (Ed.), *Women and space: Ground rules and social maps*. London: Croom Helm.
- Arhne, G. (1994). *Social organizations*. London: Sage.
- Ariès, P. (1981). *Hour of our death*. (H. Weaver, Trans.). New York, NY: Alfred A Knopf.
- Armstrong, P. (2009). *Forgetting Alvin Gouldner: CMS does reflexivity*. Paper presented at the second Conference of Practical Criticism in the Social Sciences of Management. The Management Centre. University of Leicester Jan 8th-9th 2009.
- Árnason, A. (2007). "Fall apart and put yourself together again": The anthropology of death and bereavement counselling in Britain. *Mortality*, 12(1), 48-65.
- Atkinson, P., & Coffey, A. (1997). Analysing documentary realities. In Silverman, D. (Ed.), *Qualitative research: Theory, method and practice* (pp. 80-98). London: Sage.
- Avis, M. (2005). Is there an epistemology for qualitative research? In Holloway, I. (Ed.), *Qualitative research in health care* (pp. 3-16). Maidenhead: Open University Press.
- Beech, N. (2011). Liminality and the practices of identity reconstruction. *Human Relations*, 64(2), 285-302.
- Berger, P., & Luckmann, T. (1991). *The social construction of reality: A treatise in the sociology of knowledge*. London: Penguin Books. (Original work published 1966).
- Berry, P., & Planalp, S. (2008). Ethical issues for hospice volunteers. *American Journal of Hospice and Palliative Care*, 25(6), 458-462.
- Blane, D. (1991). Health professions. In Scambler, G. (Ed.), *Sociology as applied to medicine* (pp. 221-235). London: Bailliere Tindall.
- Blauner, R. (1966). Death and social structure. *Psychiatry: Interpersonal and Biological Processes*, 29(4), 378-394.
- Bond, J. (1992). The politics of caregiving: The professionalisation of informal care. *Ageing and Society*, 12(1), 5-21.
- Boyle, D., Crilly, T., & Malby, R. (2017). *Can volunteering help create better health and care?* Retrieved on 13 January 2020 from <http://researchopen.lsbu.ac.uk/1625/>
- Brewer, J.D. (2000). *Ethnography*. Buckingham: The Open University.

- British Medical Association (BMA). (n.d.). *Confidentiality*. Retrieved on 20 June 2019 from <https://www.bma.org.uk/advice/employment/ethics/medical-students-ethics-toolkit/9-confidentiality>
- British Sociological Association (BSA). (2002). *Statement of ethical practice for the British Sociological Association*. Durham: BSA. Retrieved on 28 April 2014 from <http://www.britisoc.co.uk/about/equality/statement-of-ethical-practice.aspx>
- Brown, M. V. (2011a). How they cope: A qualitative study of the coping skills of hospice volunteers. *American Journal of Hospice and Palliative Care*, 28(6), 398-402.
- Brown, M. V. (2011b). The stresses of hospice volunteer work. *American Journal of Hospice and Palliative Care*, 28(3), 188-192.
- Buck, D. (2016). *A social movement for health? It's already here – it's called volunteering*. London: Kings Fund. Retrieved on 13 January 2020 from www.kingsfund.org.uk/blog/2016/02/social-movement-for-health
- Burbeck, R., Candy, B., Low, J., & Rees, R. (2014). Understanding the role of the volunteer in specialist palliative care: A systematic review and thematic synthesis of qualitative studies. *BMC Palliative Care*, 13(3).
- Burbeck, R., Low, J., Sampson, E.L., Bravery, R., Hill, M., Ockenden, N., Morris, S., Payne, S., & Candy, B. (2014). Volunteers in specialist palliative care: A survey of adult services in the UK. *Journal of Palliative Medicine*, 17(5), 568-574.
- Burbeck, R., Sampson, E. L., Scott, R., Bravery, R., Low, J., & Candy, B. (2015). Volunteer activity in specialist paediatric palliative care: A national survey. *BMJ Palliative and Supportive Care*, 5(3), 287–293.
- Burbeck, R., & Willig, C. (2014). The personal experience of dysmenorrhoea: An interpretative phenomenological analysis. *Journal of Health Psychology*, 19(10), 1334-1344.
- Caduri, A., & Weiss-Gal, I. (2015). Social workers who work with and without volunteers: Comparison of perceptions, organisational culture, training and experience. *British Journal of Social Work*, 45(8), 2458-2475.
- Candy, B., France, R., Low, J., & Sampson, E.L. (2015). Does involving volunteers in the provision of palliative care make a difference to patient and family wellbeing? A systematic review of quantitative and qualitative evidence. *International Journal of Nursing Studies*, 52(3), 756-768.
- Casiday, R., Kinsman, E., Fisher, C., & Bamba, C. (2008). *Volunteering and health: What impact does it really have? Final report to Volunteering England*. London: Volunteering England.
- Christians, C.G. (2005). Ethics and politics in qualitative research. In Denzin, N. K., & Lincoln, Y. S. (Eds.), *The Sage handbook of qualitative research (3rd ed.)* (pp. 139-164). Thousand Oaks, CA: Sage.
- Clark, D. (1998). Originating a movement: Cicely Saunders and the development of St Christopher's Hospice, 1957-1967. *Mortality*, 3(1), 43-63.
- Clark, D. (1999a). Cradled to the grave? Terminal care in the United Kingdom, 1948-67. *Mortality*, 4(3), 225-247.
- Clark, D. (1999b). Total pain. disciplinary power and the body in the work of Cicely Saunders, 1958–1967. *Social Science & Medicine*, 49(6), 727-736.

- Clark, D. (2007). Hospice in historical perspective. *Encyclopedia of Death and Dying*. Retrieved on 22 April 2014 from <http://www.deathreference.com/Ho-Ka/Hospice-in-Historical-Perspective.html>
- Claxton-Oldfield, S. (2013). Motivations of British hospice volunteers. *American Journal of Hospice and Palliative Medicine*, 30(6), 579-586.
- Claxton-Oldfield, S., & Blacklock, K. (2017). Hospice palliative care volunteers as program and patient/family advocates. *American Journal of Hospice and Palliative Care*, 34(9), 844-848.
- Coffey, A. (1999). *The ethnographic self: Fieldwork and the representation of identity*. London: Sage.
- Conn, L.G., Haas, B., Cuthbertson, B.H., Amaral, A.C., Coburn, N., & Nathens, A.B. (2016). Communication and culture in the surgical intensive care unit: Boundary production and the improvement of patient care. *Qualitative Health Research*, 26(7), 895-906.
- Conservative Party. (2010). *The Conservative Party manifesto 2010* [online]. The Conservative Party. Retrieved on 17 June 2019 from <https://www.conservatives.com/~media/Files/Manifesto2010>
- Corr, C. (2007). Hospice: Achievements, legacies, & challenges. *OMEGA — Journal of Death and Dying*, 56(1), 111-120.
- Cotton, P. (1989). Confidentiality: A sacred trust under siege. *Medical World News*, 54+. *Academic OneFile*. Retrieved on 23 October 2018 from <http://link.galegroup.com/apps/doc/A7494505/AONE?u=tou&sid=AONE&xid=2224e486>
- Czarniawska, B., & Mazza, C. (2003). Consulting as a liminal space. *Human Relations*, 56(3), 267-290.
- Darke, J., & Gurney, C. (2000). Putting up? Gender, hospitality and performance. In Lashley, C. & Morrison, A. (Eds.), *In Search of hospitality: Theoretical perspectives and debates* (pp. 77-97). Oxford/Woburn, M.A.: Butterworth-Heinemann.
- Davies, C. (2001). Professionalism and the conundrum of care. In Davey, B., Gray, A., & Seale, C. (Eds.), *Health and disease: A reader* (3rd ed.) (pp. 346-351). Buckingham: Open University Press.
- De Laine, M. (2000). *Fieldwork, participation and practice: Ethics and dilemmas in qualitative research*. London, UK: Sage.
- Delamont, S. (2004). Ethnography and participant observation. In Seale, C., Gobo, G., Gubrium, J.F., & Silverman, D. (Eds.), (2007). *Qualitative research practice* (pp. 205-217). London: Sage.
- Delanty, G., & Strydom, P. (2003). *Philosophies of social science: The classic and contemporary readings*. Maidenhead: Open University Press.
- DelVecchio Good, M-J., Gadmer, N.M., Ruopp, P., Lakoma, M., Sullivan, A.M., Redinbaugh, E., Arnold, R.M., & Block, S.D. (2004). Narrative nuances on good and bad deaths: Internists' tales from high-technology work places. *Social Science and Medicine*, 58(5), 939-953.
- Denzin, N. K., & Lincoln, Y. S. (Eds.). *The Sage handbook of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage.
- Department for Digital, Culture, Media & Sport (2018). *Community life survey, England 2018 to 2019: Formal volunteering fact sheet*. Retrieved on 13 January 2020 from <https://www.gov.uk/government/statistics/community-life-survey-2018-19>
- Department of Health (DOH). (2008). *End-of-life care strategy - promoting high quality care for all adults at the end of life*. Retrieved on 12 June 2014 from

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf

- DeWalt, K.M., & DeWalt, B.R. (2011). *Participant observation: A guide for fieldworkers* (2nd ed.). Plymouth: Altamira Press.
- Donald, J., & Hall, S. (1986). *Politics and ideology: A reader*. Milton Keynes: Open University Press.
- Douglas, M. (1975). Deciphering a meal. In Douglas, M. (Ed.), *Implicit meanings: Essays in anthropology* (pp. 249-275). London: Routledge and Kegan Paul.
- Douglas, M. (2002). *Purity and danger: An analysis of concept of pollution and taboo*. Abingdon: Routledge. (Original work published 1966).
- Douglas, M., & Nicod, M. (1974). Taking the biscuit: The structure of British meals. *New Society*, 30(637), 744-47.
- Du Boulay, S., & Rankin, M. (2007). *Cicely Saunders: The founder of the modern hospice movement*. London: SPCK.
- Eliasoph, N. (2011). *Making volunteers: Civic life after welfare's end*. Princeton: Princeton University Press.
- Emerson, R., Fretz, R.I. & Shaw, L.L. (2011). *Writing ethnographic fieldnotes* (2nd ed.). Chicago/London: Chicago University Press.
- Etkind, S.N., Bone, A. E., Gomes, B., Lovell, N., Evans, C. J., Higginson, I.J., & Murtagh, F.E.M. (2017). How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine*, 15(1), 102.
- Evetts, J. (1999). Professionalisation and professionalism: Issues for interprofessional care. *Journal of Interprofessional Care*, 13(2), 119-128.
- Fawcett, J. (2017). Thoughts about nursing conceptual models and the "Medical Model". *Nursing Science Quarterly*, 30(1), 77-80.
- Fenton, W., Polzin, G., Arkesden, J., & McCaffrey, R. (2019). *Skills for care: The size and structure of the adult social care sector and workforce in England, 2019*. Leeds: Skills for Care.
- Field, D., & James, N. (1993). Where and how people die. In D. Clark (Ed.), *The future for palliative care: Issues of policy and practice* (pp. 6-29). Buckingham: Open University Press.
- Field, D., & Johnson, I. (1993). Volunteers in the British hospice movement. In Clark, D. (Ed.), *The sociology of death: Theory, culture, practice* (pp. 198-217). Oxford: Blackwell.
- Field, D., Payne, S., Relf, R., & Reid, R. (2007). Some issues in the provision of adult bereavement support by UK hospices. *Social Science & Medicine*, 64(2), 428-438.
- Field-Richards, S.E., & Arthur, A. (2012). Negotiating the boundary between paid and unpaid hospice workers: A qualitative study of how hospice volunteers understand their work. *American Journal of Hospice and Palliative Medicine*, 29(8), 627-631.
- Finn, P.L., Miller, B., & Runnion, V.M. (1987). Volunteer stress and burnout: Issues for administrators. *Hospice Journal*, 3(2-3), 165-183.
- Foley, D.E. (2002). Critical ethnography: The reflexive turn. *International Journal of Qualitative Studies in Education*, 15(4), 469-490.

- Foucault, M. (1977) *Discipline and punish: The birth of the prison*. (A. Sheridan, Trans.). London: Allen Lane. (Original work published 1975).
- Foucault, M. (1986). Of other spaces. (J. Miskowiec, Trans.). *Diacritics*, 16, 22–27. (Original work published 1984.)
- Fox, N.J. (1992). *The social meaning of surgery*. Buckingham: Open University Press.
- Freud, S. (1917). Mourning and melancholia. In Strachey, J. (Ed.), (1957), *The standard edition of the complete psychological works of Sigmund Freud*, vol. 14. London: Hogarth Press.
- Froggatt, K.A. (1997). Rites of passage and the hospice culture. *Mortality*, 2(2), 123-136.
- Froggatt, K.A., & Walter T. (1995). Hospice logos. *Journal of Palliative Care*, 11(4), 39-47.
- Galea, A., Naylor, C., Buck, D., & Weeks, L. (2013). *Volunteering in acute trusts in England: Understanding the scale and impact*. London: The King's Fund.
- Ganesh, S., & McAllum, K. (2009). Discourses of volunteerism. *Annals of the International Communication Association*, 33(1), 343-383.
- Ganesh, S., & McAllum, K. (2012). Volunteering and professionalization: Trends in tension? *Management Communication Quarterly*, 26(1), 152-158.
- Garsten, C. (1999). Betwixt and between: Temporary employees as liminal subjects in flexible organizations. *Organization Studies*, 20(4), 601-617.
- Geertz, C. (1973). Thick description: Toward an interpretive theory of culture. In Geertz, C. *The interpretation of cultures: Selected essays* (pp. 3-30). New York: Basic Books.
- Gergen, K. (1994). *Realities and relationships: Soundings in social construction*. Cambridge, MA: Harvard University Press.
- Gieryn, T.F. (1983). Boundary-work and the demarcation of science from non-science: Strains and interests in professional ideologies of scientists. *American Sociological Review*, 48(6), 781–795.
- Gieseking, J.J., Mangold, W., Katz, C., Low, S., & Saegert, S. (Eds.). (2014). *The people, place, & space reader*. New York, NY: Routledge.
- Gillard, S.G., Edwards, C., Gibson, S.L., Owen, K., & Wright, C. (2013). Introducing peer worker roles into UK mental health service teams: A qualitative analysis of the organisational benefits and challenges. *BMC Health Services Research*, 13, 188.
- Glaser, B.G., & Strauss, A. I. (1965). *Awareness of dying*. Chicago: Aldine.
- Glyn Hughes, H.L. (1960). *Peace at the last*. London: The Calouste Gulbenkian Foundation.
- Goffman, I. (1986). *Frame analysis: An essay on the organization of experience*. Boston: Northeastern University Press. (Original work published 1974).
- Goffman, I. (1990). *The presentation of self in everyday life*. London: Penguin. (Original work published 1959).
- Gold, R L. (1958). Roles in sociological field observations. *Social Forces*, 36(3), 217-223.
- Gouldner, A. (1970). Towards a reflexive sociology. In Delanty, G. & Strydom, P. (Eds.), (2003), *Philosophies of social science: The classic and contemporary readings* (pp. 267-287). Maidenhead: The Open University Press.
- Green, J., & Thorogood, N. (2004). *Qualitative methods for health research*. London: Sage.

- Griffiths, C., & Brock, A. (2003). *Twentieth century mortality trends in England and Wales*. Retrieved on 2 November 2017 from <https://www.ons.gov.uk/ons/rel/hsq/health-statistics-quarterly/no--18--summer-2003/twentieth-century-mortality-trends-in-england-and-wales.pdf>
- Grint, K. (1991). *The sociology of work: An introduction*. Oxford: Polity.
- Guirguis-Younger, M., & Grafanaki, S. (2008). Narrative accounts of volunteers in palliative care settings. *American Journal of Hospice and Palliative Medicine*, 25(1), 16-23.
- Guirguis-Younger, M., Kelley, M.L., & McKee, M. (2005). Professionalisation of hospice volunteer practices: What are the implications? *Palliative and Supportive Care*, 3(2), 143-4.
- Hallman, H.L., & Burdick, M.N. (2015). *Community fieldwork in teacher education: Theory and practice*. New York, US and Oxford: Routledge.
- Hallstein, A. (1992). Spiritual opportunities in the liminal rites of hospitalization. *Journal of Religion and Health*, 31(3), 247-254.
- Hammersley, M. (1988). *Reading ethnographic research: A critical guide*. London: Longman.
- Hammersley, M. (1990). What's wrong with ethnography? The myth of theoretical description. *Sociology*, 24(4), 597-615.
- Hammersley, M. (2005). *Ethnography: Problems and prospects*. Talk given in the Qualitative Research Methodology Seminar Series, January 2005, University of Southampton and ESRC National Centre for Research Methods.
- Hammersley, M. (2008) *Questioning Qualitative Inquiry*. London: Sage Publications.
- Hammersley, M., & Atkinson P. (2007). *Ethnography: Principles in practice* (3rd ed.). London: Routledge.
- Hanna, S. (1975). *The volunteer as part of the hospice team*. Unpublished report, St Christopher's Hospice, London.
- Hardy, C., Palmer, I., & Phillips, N. (2000). Discourse as a strategic resource. *Human Relations*, 53(9), 1227-1248.
- Harris, C. (1991). In-home respite care: A comparison of volunteers and paid workers. *Journal of Volunteer Administration*, 10(1), 1-14.
- Hart, B., Sainsbury, P., & Short, S. (1998). Whose dying? A sociological critique of the 'good death'. *Mortality*, 3(1), 65-77.
- Hartley, N. (2013). Volunteering at Saint Christopher's Hospice, London: Current trends and future challenges. *Médecine Palliative*, 11(5), pp. 252-161.
- Hatziaandreu, E., Archontakis, F., & Daly, A. (2008). *The potential cost savings of greater use of home- and hospice-based end of life care in England*. The RAND Corporation: Santa Monica, California.
- Heaven, B., Bamford, C., May, C., & Moynihan, P. (2013). Food work and feeding assistance on hospital wards. *Sociology of Health & Illness*, 35(4), 628-42.
- Helman, C. (2007). *Culture, health and illness* (5th ed.). London: Hodder Arnold.
- Help the Hospices. (2006). *Volunteer value: A pilot survey of UK hospices*. London: Help the Hospices.
- Help the Hospices. (2007). *Volunteer value: A toolkit for measuring the economic value of hospice volunteers*. London: Help the Hospices.
- Help the Hospices. (2012). *Volunteers: Vital to the future of hospice care*. London: Help the Hospices.

- Help the Hospices. (2013). *Future ambitions for hospice care: Our mission and our opportunity. The final report of the Commission into the Future of Hospice Care*. London: Help the Hospices.
- Hepple, J., Kipps, M., & Thomson, J. (1990). The concept of hospitality and an evaluation of its applicability to the experience of hospital patients. *International Journal of Hospitality Management*, 9(4), 305-318.
- Hillier, R. (1988). Palliative medicine, a new specialty. *British Medical Journal*, 297(6653), 874-875.
- Hinton, J. (1972). *Dying*, 2nd ed. Harmondsworth: Penguin.
- Hoad, P. (1991). Volunteers in the independent hospice movement. *Sociology of Health & Illness*, 13(2), 231-248.
- Hoad, P. (2002). Drawing the line: The boundaries of volunteering in the community care of older people. *Health and Social Care in the Community*, 10(4), 239-246.
- Hochschild, A.R. (1979). Emotion work, feeling rules, and social structure. *American Journal of Sociology*, 85(3), 551-575.
- Hochschild, A.R. (1983). *The managed heart: Commercialization of human feeling*. Berkley, C.A.: University of California Press.
- Hockey, J.L. (1990). *Experiences of death: An anthropological account*. Edinburgh: Edinburgh University Press.
- Hockey, J.L. (1999). The ideal of home: Domesticating the institutional space of old age and death. In Chapman, T., & Hockey, J. L., (1999), *Ideal homes?: Social change and domestic life* (pp.108-118). London; New York, NY: Routledge.
- Holland, C.E. (1993). An ethnographic study of nursing culture as an exploration for determining the existence of a system of ritual. *Journal of Advanced Nursing*, 18(9), 1461-1470.
- Hollows, J. (2008). *Domestic cultures*. Maidenhead: McGraw Hill/Open University Press.
- Holly, C., & Poletick, E. (2014). A systematic review on the transfer of information during nurse transitions in care. *Journal of Clinical Nursing*, 23(17-18), 2387-2396.
- Hopkinson, J. (2002). The hidden benefit: The supportive function of the nursing handover for qualified nurses caring for dying people in hospital. *Journal of Clinical Nursing*, 11(2), 168-175.
- Hopper, H., & Skirton, H. (2016). Factors influencing the sustainability of volunteer peer support for breast-feeding mothers within a hospital environment: An exploratory qualitative study. *Midwifery*, 32, 58-65.
- Hornung, L., Egan, J., & Jochum, V. (2017). *Getting involved: How people make a difference*. London: NCVO.
- Howarth, G. (1996). *Last rites: The work of the modern funeral director*. Amityville/New York, NY: Baywood.
- Howarth, G. (2007). *Death and dying: A sociological introduction*. Cambridge, UK: Polity Press.
- Howlett, S. (2009). Setting the scene: The landscape of volunteering. In Scott, R., Howlett, S., & D. Doyle (Eds.), *Volunteers in hospice and palliative care. A resource for voluntary service managers* (2nd ed.). Oxford/New York: Oxford University Press.

- Hubbard, G., Backett-Milburn, K., & Kemmer, D. (2001). Working with emotion: Issues for the researcher in fieldwork and teamwork. *International Journal of Social Research Methodology*, 4(2), 119-137.
- Hughes, E. (1958). *Men and their work*. Glencoe: Free Press of Glencoe.
- Humphreys, M., & Brown, A. D. (2002). Narratives of organizational identity and identification: A case study of hegemony and resistance. *Organizational Studies*, 23(3), 421-447.
- Hurdley, R. (2010). The power of corridors: Connecting doors, mobilising materials, plotting openness. *Sociological Review*, 58(1), 45-64.
- Hussein, S. (2011). Volunteers in the formal long-term care workforce. *Social Care Workforce Periodical*, issue 13.
- Hyde, V., Skirton, H., & Richardson, J. (2011). Palliative day care: A qualitative study of service users' experiences in the United Kingdom. *Nursing and Health Sciences*, 13(2), 178-183.
- Institute for Volunteering Research (IVR). (2003). *Volunteers in hospices and palliative care 2003: A report of three surveys. Report 1: Survey of hospice volunteer managers/coordinators*. London: Institute for Volunteering Research.
- Jack, B.A., Kirton, J., Birakurataki, J., & Merriman, A. (2011). A bridge to the hospice: The impact of a community volunteer programme in Uganda. *Palliative Medicine*, 25(7), 706-715.
- James, N. (1989). Emotional labour: Skill and work in the social regulation of feelings. *The Sociological Review*, 37(1), 15-42.
- James, N. (1992). Care = organisation + physical labour + emotional labour. *Sociology of Health and Illness*, 14(4), 488-509.
- James, N. (1994). From vision to system: The maturing of the hospice movement. In Lee, R., & Morgan, D. (Eds.), (1996), *Death rites: Law and ethics at the end of life* (pp. 102-130). London: Routledge.
- James, N., & Field, D. (1992). The routinization of hospice: Charisma and bureaucratization. *Social Science and Medicine*, 34(12), 1363-1375.
- Jenkins, T. (2014). Clothing norms as markers of status in a hospital setting: A Bourdieusian analysis. *Health*, 18(5), 526-541.
- Jenkinson, C. E., Dickens, A.P., Jones, K., Thompson-Coon, J., Taylor, R.S., Rogers, M., Bambra, C.K., Lang, I., & Richards, S.H. (2013). Is volunteering a public health intervention? A systematic review and meta-analysis of the health and survival of volunteers. *BMC Public Health*, 13, 773.
- Joint National Cancer Survey Committee of the Marie Curie Memorial and the Queen's Institute of District Nursing (JNCSC). (1952). *Report on a national survey concerning patients with cancer nursed at home*. Chairman, Ronald Raven. London.
- Junker, B. (1952). Some suggestions for the design of field work learning experiences. In Hughes, E.C., Junker, B., Gold R., and Kittel D. (Eds.), *Cases in field work*. Chicago: University of Chicago.
- Kelemen, M., Mangan, A., & Moffat, S. (2017). More than a 'little act of kindness'? Towards a typology of volunteering as unpaid work. *Sociology*, 51(6), 1239-56.
- Kellehear, A. (2005). *Compassionate cities: Public health and end-of-life care*. London: Routledge.
- Kellehear, A. (2007). *A social history of dying*. Cambridge, UK: Cambridge University Press.

- Kellehear, A. (2013). Compassionate communities: End-of-life care as everyone's responsibility. *QJM: An International Journal of Medicine*, 106(12), pp. 1071–1075.
- Kellehear, A., Pugh, E., & Atter, L. (2009). Home away from home? A case study of bedside objects in a hospice. *International Journal of Palliative Nursing*, 15(3), 148-52.
- King, C. (1995). What is hospitality? *International Journal of Hospitality Management*, 14(3), 219-234.
- Kitchen, S., Michaelson, J., Wood, N., & John, P. (2006). *2005 citizenship survey: Active communities topic report*. London: Department for Communities & Local Government.
- Klass, D., Nickman, S.L., & Silverman, P. R. (1996). *Continuing bonds: New understandings of grief*. Washington, DC: Taylor & Francis.
- Komaromy, C. (2000). The sight and sound of death: The management of dead bodies in residential and nursing homes for older people. *Mortality*, 5(3), 299–315.
- Komaromy, C. (2002). *The performance of the hour of death*. In Clark, D., & Hockey, J. (Eds.), *Palliative care for older people in care homes* (pp. 138-150). Buckingham: Open University Press.
- Komaromy, C. (2005). *The production of death and dying in care homes for older people: An ethnographic account*. Unpublished Doctoral Thesis, The Open University.
- Komaromy, C., & Hockey, J.L. (2001). 'Naturalizing' death among older adults in residential care. In Hockey, J., Katz, J., & Small, N. (Eds.), *Grief, mourning, and death ritual* (pp. 73-81). Buckingham: Open University Press.
- Krutkowski, S. (2014). *Understanding volunteer expectations and motive fulfilment*. London: True Volunteer Foundation.
- Kubler-Ross, E. (1969). *On death and dying*. New York: Macmillan.
- Laing, R. (1971). Politics of the family and other essays. Retrieved on 6 December 2018 from https://archive.org/stream/in.ernet.dli.2015.130664/2015.130664.The-Politics-Of-The-Family-And-Other-Essays_djvu.txt
- Langley-Evans, A., & Payne, S. (1997). Light-hearted death talk in a palliative day care context. *Journal of Advanced Nursing*, 26(6), 1091-1097.
- Lashley, C. (2000). Towards a theoretical understanding. In Lashley, C., & Morrison, A. (Eds.), *In search of hospitality: Theoretical perspectives and debates* (pp. 1-17). Oxford/ Woburn, MA: Butterworth-Heinemann.
- Lashley, C., & Morrison, A. (2000). Introduction. In Lashley, C., & Morrison, A. (Eds.), *In search of hospitality: Theoretical perspectives and debates* (pp. xv-xvi). Oxford/Woburn, MA: Butterworth-Heinemann.
- Lawler, J. (1991). *Behind the screens: Nursing, somology, and the problem of the body*. Edinburgh: Churchill Livingstone.
- Lawton, J. (2000). *The dying process: Patients' experiences of palliative care*. London: Routledge.
- Lefebvre, H. (1991). *The production of space*. (D. Nicholson-Smith, Trans.). Oxford: Blackwell. (Original work published 1974).
- Leming, M.R. (2003). The history of the hospice approach. In Bryant, C.D., & Peck, D.L. (Eds.), *Handbook of death and dying* (pp. 485-494). Thousand Oaks: Sage.

- Lewis, M.J. (2007). *Medicine and care of the dying: A modern history*. Oxford: Oxford University Press.
- Liamputtong, P. (2007). *Researching the vulnerable: A guide to sensitive research methods*. London: Sage.
- Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, 101, 141-148.
- Littlewood, J. (1993). The denial of death and rites of passage in contemporary societies. In Clark, D. (Ed.), *The Sociology of Death* (pp. 69-84). Oxford: Blackwell.
- Luijckx, K.G., & Shols, J.M.G.A. (2009). Volunteers in palliative care make a difference. *Journal of Palliative Care*, 25(1), 30-39.
- Lupton, D. (1996). *Food, the body and the self*. London: Sage.
- Lupton, D. (1998). *The emotional self: A sociocultural exploration*. London: Sage.
- Lynch, P., Molz, J. G., McIntosh, A., Lugosi, P., & Lashley, C. (2011). Theorizing hospitality. *Hospitality & Society*, 1(1), 3-24.
- Machado, C., Korein, J., Ferrer, Y., Portela, L., García, M. de La C., Chinchilla, M., Machado, Y., & Manero, J. M. (2007). The declaration of Sydney on human death. *Journal of Medical Ethics*, 33(12), 699-703.
- Malinowski, B. (1922). *Argonauts of the Western Pacific*. London: Routledge.
- Manning, P. (1992). *Erving Goffman and modern sociology*. Polity Press: Cambridge.
- Martin, D., Nettleton, S., Buse, C., Prior, L., & Twigg, J. Architecture and health care: A place for sociology. *Sociology of Health and Illness*, 37(7), 1007-1022.
- McDaid, P. (1995). Day care. In Penson, J., & Fisher, R. (Eds.), (2002), *Palliative care for people with cancer* (2nd ed.) (pp. 150-157). London: Edward Arnold.
- McDonnell, A., McKeown, J., Keen, C., Palfreyman, J., & Bennett, N. (2014). Introducing on-ward volunteers to work with patients with dementia. *Nursing Older People*, 26(4), 28-33.
- McGann, S. (2013). *The production of hospice space: conceptualising the space of caring and dying*. Farnham: Ashgate Press.
- McGarvey, A., Jochum, V., Davies, J., Dobbs, J., & Hornung, L. (2019). *Time well spent: A national survey on the volunteer experience*. London: NCVO.
- McInerney, F. (1992). Provision of food and fluids in terminal care: A sociological analysis. *Social Science in Medicine*, 34, 1272-1276.
- McKee, M., Kelley, M.L., Guirguis-Younger, M., MacLean, M., & Nadin, S. (2010). It takes a whole community: The contribution of rural hospice volunteers to whole-person palliative care. *Journal of Palliative Care*, 26(2), 103-111.
- Merrell, J. (2000). Ambiguity: Exploring the complexity of roles and boundaries when working with volunteers in well woman clinics. *Social Science and Medicine*, 51(1), 93-102.
- Miller, D. 1984. Modernism and suburbia as material ideology. In Miller, D., & Tilley, C. (Eds.), *Ideology, Power and Prehistory* (pp. 37-50). Cambridge: University Press.
- Mohan, J., & Bulloch, S. (2012). *The idea of a 'civic core': What are the overlaps between charitable giving, volunteering, and civic participation in England and Wales?* Birmingham, UK: Third Sector Research Centre.

- Moisio, R., Arnould, E., & Price, L. (2004). Between mothers and markets: Constructing family identity through homemade food. *Journal of Consumer Culture*, 4(3), 361-384.
- Morris, S.M., Payne, S., Ockenden, N., & Hill, M. (2017). Hospice volunteers: Bridging the gap to the community? *Health and Social Care in the Community*, 25(6), 1704-1713.
- Morris, S., Wilmot, A., Hill, M., Ockenden, O., & Payne, S. (2013). A narrative literature review of the contribution of volunteers in end-of-life care services. *Palliative Medicine*, 27(5), 428-436.
- National Council for Palliative Care (NCPC). (n.d.). *Palliative care explained*. Retrieved on 8 April 2014 from <http://www.ncpc.org.uk/palliative-care-explained>
- National Council for Palliative Care (NCPC). (2013). *National survey of patient activity data for specialist palliative care services. MDS full report for the year 2011-2012*. London: National Council for Palliative Care.
- Naylor, C., Mundle, C., Weeks, L., & Buck, D. (2013). *Volunteering in health and care: Securing a sustainable future*. London: The King's Fund.
- Nesbit, R., Christensen, R., & Brudney, J. (2018). The limits and possibilities of volunteering: A framework for explaining the scope of volunteer involvement in public and nonprofit organizations. *Public Administration Review*, 78(4), 502-513.
- Netting, F., Nelson, H., Borders, K., & Huber, R. (2004). Volunteer and paid staff relationships: Implications for social work administration. *Administration in Social Work*, 28(3-4), 69-89.
- Nursing and Midwifery Council (2018). *The code: Professional standards of practice and behaviour for nurses, midwives and nursing associates*. Retrieved on 24 April 2019 from <https://www.nmc.org.uk/standards/code>
- Oakley, A. (1974). *The sociology of housework*. London: Martin Robinson.
- Office for National Statistics (ONS). (2013). *Summary Results, 2012-based national population projections*. Retrieved on 21 April 2014 from www.ons.gov.uk/ons/dcp171776_334073.pdf
- Office for National Statistics (ONS). (2014). *Mortality statistics: Deaths registered in England and Wales by area of usual residence, 2012*. Retrieved on 20 March 2014 from <http://www.ons.gov.uk/ons/rel/vsob1/deaths-registered-area-usual-residence/2012/rft-deaths-area-package-2012.xls>
- Office for National Statistics (ONS). (2018). *Deaths by marital status place of death, England, 2017 registrations*. Retrieved on 8 July 2019 from <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/009430deathsby marital status and place of death england 2017 registrations>
- O'Toole, P., & Were, P. (2008). Observing places: Using space and material culture in qualitative research. *Qualitative Research*, 8(5), 616-34.
- Ottrey, E., Palermo, C., Huggins, C.E., & Porter, J. (2018). Exploring staff perceptions and experiences of volunteers and visitors on the hospital ward at mealtimes using an ethnographic approach. *Journal of Clinical Nursing*, 27(7-8), e1571-e1579.
- Overgaard, C. (2015). The boundaries of care work: A comparative study of professionals and volunteers in Denmark and Australia. *Health and Social Care in the Community*, 23(4), 380-388.

- Overy, C., & Tansey, E M. (Eds.). (2013). *Palliative medicine in the UK c.1970–2010*. Wellcome Witnesses to Twentieth Century Medicine, 45. London: Queen Mary, University of London.
- Palgi, P., & Abramovitch, H. (1984). Death: A cross cultural perspective. *Annual Review of Anthropology*, 13, 385-417.
- Paradis, L., & Cummings, S. (1986). The evolution of hospice in America toward organizational homogeneity. *Journal of Health and Social Behavior*, 27(4), 370-386.
- Parkes, C.M. (1972). *Bereavement studies of grief in adult life*. London: Tavistock.
- Paul, S., & Sallnow, L. (2013). Public health approaches to end-of-life care in the UK: An online survey of palliative care services. *BMJ Supportive & Palliative Care*, 3, 196-199.
- Payne, S.A. (2002). Dilemmas in the use of volunteers to provide hospice bereavement support: Evidence from New Zealand. *Mortality*, 7(2), 139-154.
- Payne, S. (2008). Part 3: Loss and bereavement. Overview. In Payne, S., Seymour, J., & Ingleton, C. (Eds.), *Palliative care nursing: Principles and evidence for practice* (2nd ed.) (pp. 425-448). Maidenhead: Open University Press.
- Payne, S., Hardey, M., & Coleman, P. (2000). Interactions between nurses during handovers in elderly care. *Journal of Advanced Nursing*, 32(2), 277-285.
- Payne, S., Preston, N., Turner, M., & Rolls, L. (2013). *Research in palliative care: Can hospices afford not to be involved?* Help the Hospices.
- Pearson, A., Baker, H., Walsh, K., & Fitzgerald, M. (2001). Contemporary nurses' uniforms: History and traditions. *Journal of Nursing Management*, 9(3), 147-152.
- Pope, C. (2005). Conducting ethnography in medical settings. *Medical Education*, 39(12), 1180-1187.
- Pratt, M., & Rafaeli, A. (1997). Organizational dress as a symbol of multilayered social identities. *The Academy of Management Journal*, 40(4), 862-898.
- Prior, L. (1984). The rationalisation of death: The medico-legal system and the elimination of human agency. *Theory, Culture and Society*, 2(2), 55-70.
- Punch, M. (1974). The sociology of the anti-institution. *The British Journal of Sociology*, 25(3), 312-325.
- QSR. (2017). NVivo qualitative data analysis software (Version 11) [Computer software]. QSR International Pty Ltd.
- Rafaeli, A., & Pratt, M. (1993). Tailored meanings: On the meaning and impact of organizational dress. *The Academy of Management Review*, 18(1), 32-55.
- Rager, K.B. (2005). Compassion stress and the qualitative researcher. *Qualitative Health Research*, 15(3): 423-430.
- Redman, P. (1998). *D820 The challenge of the social sciences. Study guide*. The Open University.
- Relf, M. (1998). Involving volunteers in bereavement counselling. *European Journal of Palliative Care*, 5(2), 61-65.
- Richardson, M. (1999). The symbolism and myth surrounding nurses' uniform. *British Journal of Nursing*, 8(3), 169-175.
- Rochester, C. (2006). *Making sense of volunteering*. London: The Commission on the Future of Volunteering.

- Rosenhan, C. (2016). Looking both ways – a Lefebvrian investigation of Catherine Carsell's *Open the Door!* *Scottish Literary Review*, 8(2), 93-111.
- Ross, S., Fenney, D., Ward, D., & Buck, D. (2018). *The role of volunteers in the NHS: Views from the front line*. London: King's Fund.
- Roth, J.A. (1963). *Timetables*. Indianapolis/New York, NY: The Bobbs-Merrill Company Inc.
- Sallnow, L., Richardson, H., Murray, S., & Kellehear, A. (2016). The impact of a new public health approach to end-of-life care: A systematic review. *Palliative Medicine*, 30(3): 200-211.
- Sandstrom, K.L., Martin, D.D., & Fine, G.A. (2001). Symbolic interactionism at the end of the century. In Ritzer, G., & Smart, B. (Eds.), *Handbook of social theory* (pp. 217-231). London: Sage.
- Saunders, C. (n.d.). *Scheme*. Unpublished document, St Christopher's Hospice, London.
- Saunders, C. (2002). Forward. In Doyle, D. (Ed.), *Volunteers in hospice and palliative care: A handbook for volunteer service managers* (pp. vii-viii). Oxford: Oxford University Press.
- Saunders, C., & Clark, D. (2002). *Cicely Saunders: Founder of the hospice movement: Selected letters 1959-1999*. Oxford: Oxford University Press.
- Saxton, J., Harrison, T., & Guild, G. (2015). *The new alchemy: How volunteering turns donations of time and talent into human gold*. Retrieved on 30 May 2019 from http://www.sheffieldvolunteercentre.org.uk/uploads/files/The-New-Alchemy-volunteering-report_2015.pdf
- Scambler, G. (1991). Death, dying and bereavement. In Scambler, G. (Ed.), *Sociology as applied to medicine* (pp. 93-105). London: Bailliere Tindall.
- Schirato, T., Danaher, G., & Webb, J. (2012). *Understanding Foucault: A critical introduction* (2nd ed.). London: Sage.
- Scott, R., Jindal-Snape, D., & Manwaring, G. (2018). Exploring the relationship between volunteering and hospice sustainability in the UK: A theoretical model. *Journal of Palliative Nursing*, 24(5), 212-219.
- Seale, C. (1998a) *Constructing death: The sociology of dying and bereavement*. Cambridge, UK: Cambridge University Press.
- Seale, C. (1998b). Theories in health care and research: Theories and studying the care of dying people. *BMJ*, 317(7171), 1518-1520.
- Seigny, A., Dumont, S., Cohen, S.R., & Frappier, A. (2010). Helping them live until they die: Volunteer practices in palliative home care. *Nonprofit and Voluntary Sector Quarterly*, 39(4):734-752.
- Seymour, J.E. (1999). Revisiting medicalisation and 'natural' death. *Social Science and Medicine*, 49(5), 691-704.
- Seymour, J.E. (2001). *Critical moments – death and dying in intensive care*. Buckingham: Open University Press.
- Seymour, J.E. (2007). Ethnography. In Addington-Hall, J., Bruera, E., Higginson, I.J., & Payne, S. (Eds.), *Research Methods in Palliative Care*. Oxford: Oxford University Press, 211-227.
- Seymour, J.E. (2012). Looking back, looking forward: The evolution of palliative and end-of-life care in England. *Mortality*, 17(1), 1-17.

- Seymour, J.E., & Cassel, B. (2017). Palliative care in the USA and England: A critical analysis of meaning and implementation towards a public health approach. *Mortality*, 22(4), 275-290.
- Seymour, J.E., Payne, S., Reid, D., Sargeant, A., Skilbeck, J., & Smith, P. (2005). Ethical and methodological issues in palliative care studies: The experiences of a research group. *Journal of Research in Nursing*, 10(2), 169-188.
- Shilling, C. (2017). Body pedagogics: Embodiment, cognition and cultural transmission. *Sociology*, 51(6), 1205-1221.
- Small, N. (2000). The modern hospice movement: 'Bright lights sparkling' or 'a bit of heaven for a few'? In Bornat, J., Perks, R., Thompson, P., & Walmsley, J. (Eds.), *Oral history, health and welfare* (pp. 288-308). London: Routledge.
- Smith, M.J. (1998). *Social science in question*. London: Sage.
- Sommerville, A. (2013). Patient confidentiality. In Sommerville, A., English, V., Branman, S., Nathanson, V., & British Medical Association (Eds.), *Everyday medical ethics and law* (pp. 165-210). Chichester, UK: John Wiley & Sons.
- Sontag, S. (1979). *Illness as metaphor*. London: Allen Lane. (First published 1978.)
- Spradley, J. (1980). *Participant observation*. New York/London: Holt, Rinehart and Winston.
- Star, S., & Griesemer, J. (1989). Institutional ecology, 'translations' and boundary objects: Amateurs and professionals in Berkeley's museum of vertebrate zoology, 1907-39. *Social Studies of Science*, 19(3), 387-420.
- Stoddard, S. (1992). *The hospice movement: A better way of caring for the dying* (revised edition). New York, NY: Vintage Books (Random House).
- Strange, F. (1996). Handover: An ethnographic study of ritual in nursing practice. *Intensive & Critical Care Nursing*, 12(2), 106-112.
- Street, A., & Coleman, S. (2012). Introduction: Real and imagined spaces. *Space and Culture*, 15(1), 4-17.
- Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies*, 23(3), 197-224.
- Studer, S., & Schnurbein, G. (2013). Organizational factors affecting volunteers: A literature review on volunteer coordination. *VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations*, 24(2), 403-440.
- Sturdy, A., Schwarz, M., & Spicer, A. (2006). Guess who's coming to dinner? Structures and uses of liminality in strategic management consultancy. *Human Relations*, 59(7), 929-960.
- Sudnow, D. (1967). *Passing on: The social organization of dying*. Englewood Cliffs, New Jersey: Prentice Hall.
- Taylor, R. (2004). Extending conceptual boundaries: Work, voluntary work and employment. *Work, Employment & Society*, 18(1), 29-49.
- Taylor, R. (2005). Rethinking voluntary work. *Sociological Review*, 53(S2), 117-135.
- Telfer, E. (2000). The philosophy of hospitableness. In Lashley, C., & Morrison, A. (Eds.), *In search of hospitality: Theoretical perspectives and debates* (pp. 38-55). Oxford/Woburn, M.A.: Butterworth-Heinemann.

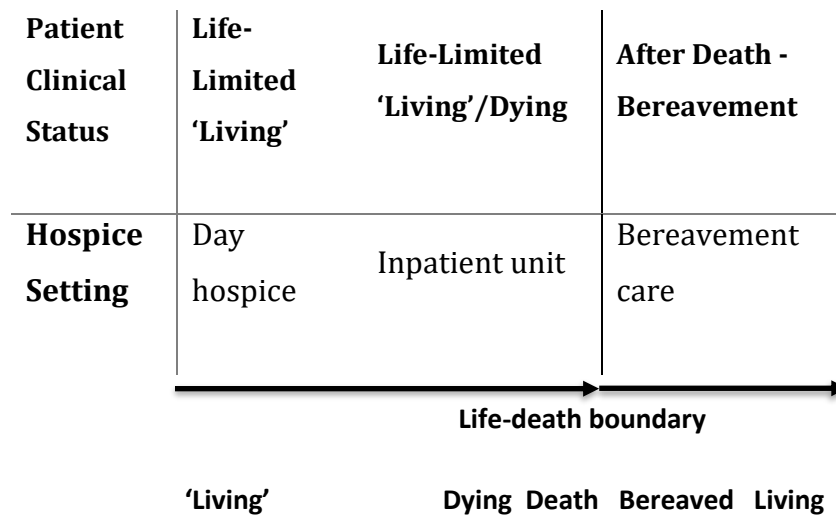
- The Royal Marsden NHS Foundation Trust (n.d.). *Nurses' roles and uniforms*. Retrieved on 19 October 2018 from <https://www.royalmarsden.nhs.uk/your-care/your-visit/nurses-roles-and-uniforms>
- Thomas, J. (1993). *Doing critical ethnography*. Newbury Park, CA, Sage.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(45).
- Thomassen, B. (2009). The uses and meanings of liminality. *International Political Anthropology*, 2(1), 5-27.
- Turner, B.S. (1987). *Medical power and social knowledge*. London: Sage.
- Turner, V.W. (1967). *Liminal to liminoid, in play, flow, and ritual: An essay in comparative symbology*. Retrieved on 15 February 2019 from https://scholarship.rice.edu/bitstream/handle/1911/63159/article_RIP603_part4.pdf;sequence=1
- Turner, V.W. (1974). *The ritual process*. Harmondsworth: Penguin Books. (Original work published 1969).
- Twigg, J. (1989). Models of carers: How do social care agencies conceptualise their relationship with informal carers? *Journal of Social Policy*, 18(1), pp. 53-66.
- Twigg, J. (2000). *Bathing the body and community care*. London: Routledge.
- Twycross, R.G. (1990). *A time to die*. London: Christian Medical Fellowship.
- Underwood, J.E. (2016). *Just a bunch of grapes? Liminality and the experiences of adult visitors to NHS acute medical and surgical wards in England*. Unpublished PhD thesis, University of Huddersfield.
- United Nations (UN). (1999). *On volunteering and social development*. Bonn/New York: United Nations.
- Van Bochove, M., Tonkens, E., Verplanke, L., & Roggeveen, S. (2018). Reconstructing the professional domain: Boundary work of professionals and volunteers in the context of social service reform. *Current Sociology*, 66(3), 392-411.
- Van Gennep, A. (1977). *The rites of passage*. (M.B. Vizedom & G.L. Caffee, Trans.). London and New York, NY: Routledge and Kegan-Paul. (Original work published 1960).
- Van Maanen, J. (2011). *Tales of the field* (2nd ed.). Chicago: The University of Chicago Press.
- Vanderstichelen, S., Cohen, J., Van Wesemael, Y., Deliëns, L., & Chambaere, K. (2018). The liminal space palliative care volunteers occupy and their roles within it: A qualitative study. *BMJ Supportive & Palliative Care*. Advance online publication. doi: 10.1136/bmjspcare-2018-001632
- Visser, M. (2017). *The rituals of dinner* (2nd ed.). Penguin Books. (Original work published (in this edition) 2008).
- Volunteer Canada. (2001). *A matter of design: Job design theory and application to the voluntary sector*. Volunteer Canada. Retrieved on 4 May 2018 from <http://hrcouncil.ca/hr-toolkit/documents/MatterofDesignEng.pdf>
- Volunteering England. (2012). *111 roles for volunteers in health and social care*. Volunteering England website. Retrieved on 4 February 2020 from <https://www.webarchive.org.uk/wayback/en/archive/20130425232758/http://www.volunteering.org.uk/resources/volunteeringinhealth/roles>
- Wagner, J. (2013). *The social life of water*. New York: Berghahn Books.

- Walford, G. (2007). Classification and framing of interviews in ethnographic interviewing. *Ethnography and Education*, 2(2), 145–157.
- Walford, G. (2018). Interviews and interviewing in the ethnography of education. In *Oxford research encyclopedia of education* [online]. Oxford University Press USA. doi: 10.1093/acrefore/9780190264093.013.320
- Walker, G., & Bryant, W. (2013). Peer support in adult mental health services: A meta-synthesis of qualitative findings. *Psychiatric Rehabilitation Journal*, 36(1), 28-34.
- Walshe, C., Ewing, G., & Griffiths, J. (2012). Using observation as a data collection method to help understand patient and professional roles and actions in palliative care settings. *Palliative Medicine*, 26(8), 1048-1054.
- Walter, T. (1991). Modern death: Taboo or not taboo? *Sociology*, 25(2), 293-310
- Walter, T. (1994). *The revival of death*. London: Routledge.
- Walter, T. (1996). Facing death without tradition. In Howarth, G., & Jupp, P. (Eds.), *Contemporary issues in the sociology of death, dying and disposal* (pp. 193–204). Basingstoke: Macmillan.
- Warde, A., & Yates, L. (2017). Understanding eating events: Snacks and meal patterns in Great Britain. *Food, Culture & Society*, 20(1), 15–36.
- Watt, N. (2010, July 19). Cameron promises power for the 'man and woman on the street'. *The Guardian*. Retrieved on 23 April 2014 from <https://www.theguardian.com/politics/2010/jul/19/david-cameron-big-society-cuts>
- Watts, J.H. (2012). Hospice volunteering: Work, socially useful leisure or just filling in time? *European Journal of Palliative Care*, 19(4), 195–197.
- Weeks, L.E., MacQuarrie, C., & Bryanton, O. (2008). Hospice palliative care volunteers: A unique care link. *Journal of Palliative Care*, 24(2), 85-93.
- White, N., Reid, F., Harris, A., Harries, P., & Stone, P. (2016). A systematic review of predictions of survival in palliative care: How accurate are clinicians and who are the experts? *PLoS ONE*, 11(8), e0161407.
- Wilkes, E. (1981). Great Britain: The hospice in Britain. In Saunders, C., Summers, D.H., & Teller, N. (Eds.), *Hospice: The living idea* (pp. 184-186). London: Arnold.
- Willig, C. (2012). Perspectives on the epistemological basis of qualitative research. In Cooper, H. (Ed.), *APA handbook of research methods in psychology: Vol. 1* (pp. 5-21). Washington: American Psychological Association.
- Wilson, J. (2000). Volunteering. *Annual Review of Sociology*, 26(1), 215-240.
- Wolkowitz, C. (2011). The organisational contours of 'body work'. In Jeanes, E.L., Knights, D., & Martin, P. Y. (Eds.), *Handbook of gender, work, and organization* (pp. 177-191). Chichester, West Sussex: Wiley.
- Woodby, L., Williams, B., Wittich, A., & Burgio, K. (2011). Expanding the notion of researcher distress: The cumulative effects of coding. *Qualitative Health Research*, 21(6), 830-838.
- Worden, J. (2003). *Grief Counselling and grief therapy: A handbook for the mental health practitioner*. New York: Springer.

- World Health Organisation (WHO). (2002). *Definition of palliative care*. Retrieved on 21 March 2014 from <http://www.who.int/cancer/palliative/definition/en/>
- Worpole, K. (2010). Making hospice space. In Hockey, J., Komaromy, C., & Woodthorpe, K. (Eds.), *The matter of death: Space, place and materiality* (pp. 35-51). Basingstoke: Palgrave Macmillan.
- Zerubavel, E. (1993). *The fine line: Making distinctions in everyday life*. Chicago/London: University of Chicago Press. (Original work published 1991).

Appendices

Appendix A Figure illustrating the life-death-life continuum



Based on Hockey, 1990, p. 163

Appendix B Patient and family information

Volunteers in Hospices Research Project

Information for patients and families

Rachel France, PhD student, The Open University, Walton Hall, Milton Keynes, MK76AA

E-mail: rachel.france@open.ac.uk; Tel: 01908 858772

Who am I?

My name is Rachel France and I am a PhD student doing a 3-year research project with The Open University.

What is my research about?

I am researching the role of volunteers in hospices, particularly volunteers with direct contact with patients and their families. Volunteers have a special place in hospices and can make a big difference, not just in terms of the financial value of their contribution, but in terms of the qualitatively different kind of care they give. I am interested in their role, what it is they do, how they do it, and how it works in practice.

Why is this important?

We know quite a lot about what volunteers do from a survey which I was involved with recently (see <http://online.liebertpub.com/doi/pdfplus/10.1089/jpm.2013.0157>). The data for this was collected by sending an online survey to volunteer managers at hospices across the UK. This gave a snapshot of what volunteers do but I would like to get more of an 'insider' view of what happens in real life, and the best way to do this is to spend time in the hospice with volunteers themselves.

How will I undertake the research?

I am spending some time in the hospice over a period of several months, in different areas where volunteers are involved with patients and their families, just observing what is happening and chatting to volunteers and staff.

Will this effect patients and their families or other visitors?

No – I am not researching patients, families or other visitors, and my research will not impact on the care the hospice provides. I am only interested in volunteers, and what they do in the hospice. I am very happy to talk about my research if you would like to ask me anything. I will be wearing a 'researcher' badge.

If you want to talk to someone else about this research from The Open University, you can contact the Director of Postgraduate Studies: **Dr Lindsay O'Dell, at the Faculty of Health and Social Care, The Open University, Walton Hall, Milton Keynes, MK76AA** [\[email\]](#)

Appendix C Information for participants

Volunteers in Hospices Research Project

Information for prospective participants

Rachel France, PhD student, The Open University, Walton Hall, Milton Keynes, MK76AA

E-mail: rachel.france@open.ac.uk; Tel: 01908 858772

Who am I?

My name is Rachel France and I am a PhD student doing a 3-year research project with The Open University.

What is my research about?

I am researching volunteers in hospices, focusing on those with direct contact with patients and their families. I am interested in the volunteer role, for example, how it differs from that of staff, and how it works in practice.

Why is this important?

Volunteers have a special place in hospices, not just in terms of the financial value of their contribution, but in terms of the qualitatively different kind of care they give. We know quite a lot about what volunteers do from a survey with which I was recently involved (available at <http://online.liebertpub.com/doi/pdfplus/10.1089/jpm.2013.0157>).

The data for this was collected by sending an online survey to volunteer coordinators and managers. However, this just provided a snapshot of what volunteers do and now I would like to get more of an 'insider' view of what happens in real life. The best way to do this is to spend time in the hospice with volunteers themselves.

How will I undertake the research?

I will spend some time in the hospice over a period of several months, in different areas where volunteers are involved with patients and their families, following different volunteers and staff, observing what is happening and chatting to volunteers and staff.

Will the information I collect remain confidential?

Yes. I will not use your name in any write up of my research, and your views and contributions will be treated totally confidentially. All materials will only be discussed with my supervisors Dr Carol Komaromy and Professor Jan Draper (contact details below). My notes will be securely stored at all times and destroyed after the research is completed and the research findings are published.

Can you leave the research?

Yes. You are free to leave the research without reason, at any time, if you no longer wish to take part. If you choose to leave the research before I begin analysing the information, all of the information you have given me will be destroyed, unless you consent to the information being used in this study.

Will there be any risks associated with you taking part?

I do not anticipate that there will be risks associated with this research. I shall be happy to discuss anything with you at any time during the research. My contact details are at the top of this information sheet.

How will the research be used in future?

Results of this research will be written up for my PhD degree, and may be published in academic journals and used for educational purposes. No individual will be identifiable.

More information

Please contact me if you would like to discuss any aspect of this research or require any further information. My e-mail and phone number are at the top of this sheet.

If you want to talk to someone else about this research from The Open University, you can contact the Director of Postgraduate Studies: **Dr Lindsay O'Dell, at the Faculty of Health and Social Care, The Open University, Walton Hall, Milton Keynes, MK76AA**

Appendix D Participant consent form

Consent to take part in the Volunteers in Hospices Research Project

Name of Project Researcher

Rachel France

I would be grateful if you could please read the following and then sign at the end – thank you

I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

☐

I understand that my participation is voluntary and that I can withdraw at any time without giving any reason.

☐

I have been assured that my confidentiality will be protected as specified in the information sheet.

☐

I agree that the information that I provide can be used for educational or research purposes, including publication.

☐

Name of participant

Date

Signature

**Name of person taking
consent**

Date

Signature

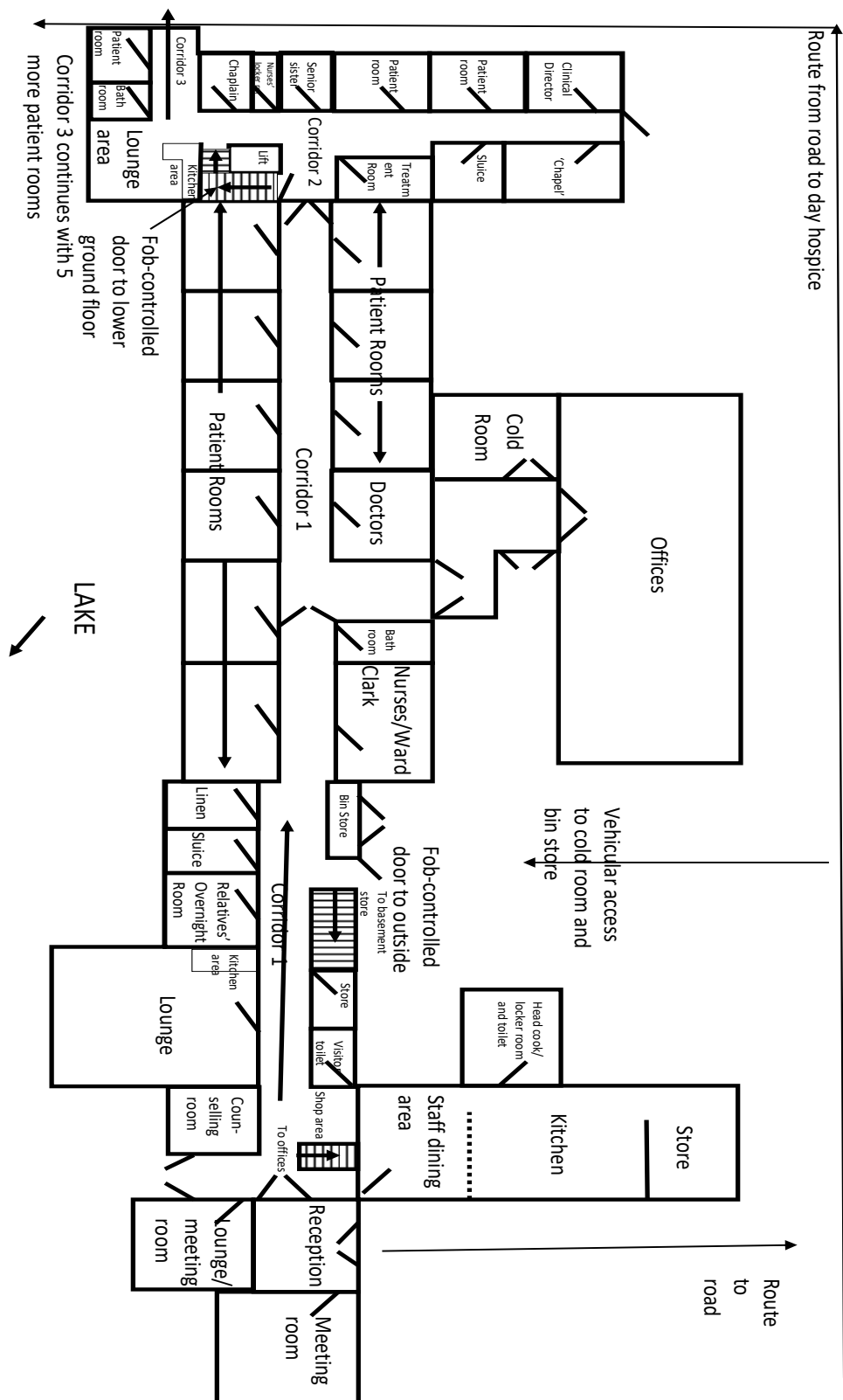
Appendix E Hospice documents accessed during fieldwork

Documents*	Flora House	Daisy Hospice
Volunteer job descriptions	Day hospice 'general' volunteer IPU lunch volunteer IPU supper volunteer Care assistant volunteer	Care assistant volunteer IPU general volunteer (covers breakfast, afternoon and supper shifts) Rehabilitation assistant
Information given to volunteers	Information for volunteers Infection control for volunteers Materials from training on adult safeguarding Materials from training with child bereavement team	Volunteer agreement Volunteer confidentiality agreement Professional conduct guidelines Infection prevention for IPU volunteers Keeping safe guidelines Agenda for volunteer induction
Written documents used by volunteers	'Crib' sheet for bereavement team telephone support	
Information for department managers	Volunteer policy	Volunteer policy Volunteer recruitment guidelines for managers Volunteer supervision form Volunteer problem solving procedure Written warning letter Ending volunteer placement guidelines and letter Referencing process Reference request letter Reference request form Volunteer leaver's form Volunteer vacancy advertisement Volunteer induction checklist
Patient leaflets	Introduction to the hospice Introduction to the day hospice Memorial services Support offered to patients and carers Carers' events	Guide to hospice services Guide to bereavement support Guide to supportive care Guide to day hospice services Hospice newsletters

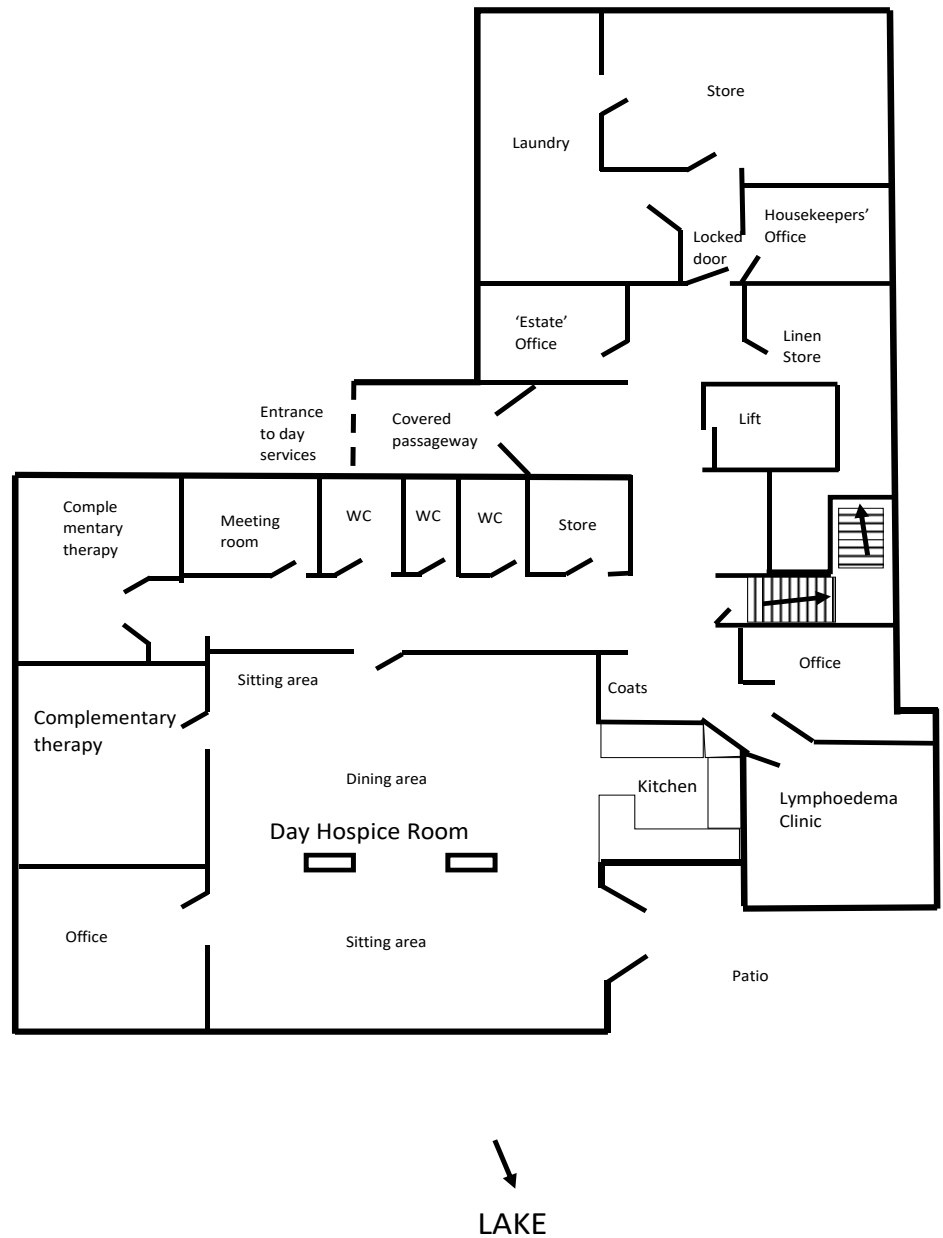
	Coffee Time guidelines General: Hospice newsletter	Day care activities and 'chit chat' Day care menu
Photographs	Photographs of posters aimed at volunteers Other photographs of the hospice spaces, buildings, grounds and the wider environment	Photographs of posters aimed at volunteers Other photographs of the hospice spaces, buildings, grounds and the wider environment

* document names use pseudonyms

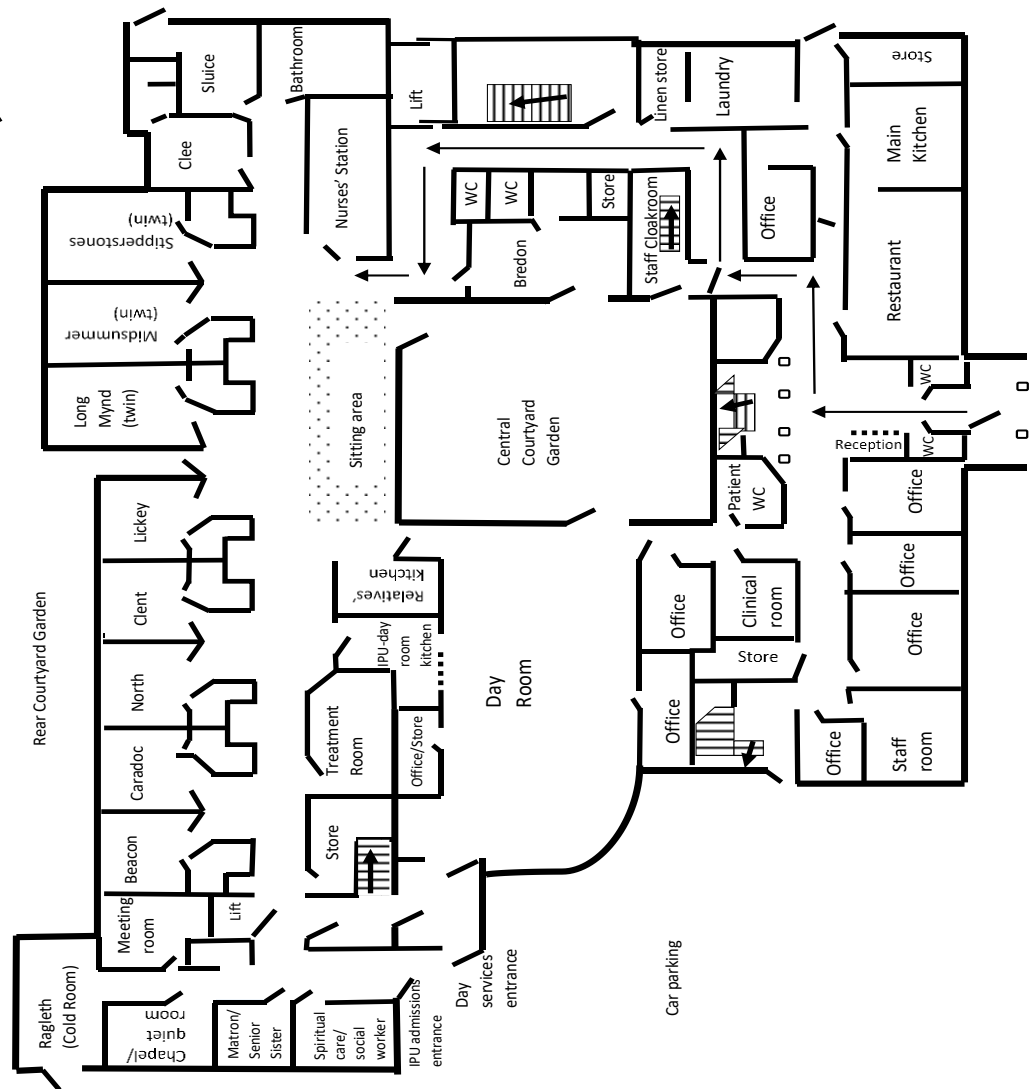
252



Appendix G Flora House Lower Ground Floor



Appendix H Daisy Hospice Floor Plan



Appendix I Findings by research question and data chapter

Research sub-question/Chapter	Chapter 4: hospice spaces and materiality	Chapter 5: day hospice 'general' volunteers	Chapter 6: inpatient unit 'general' volunteers	Chapter 7: 'professional' volunteers	Chapter 8: bereavement volunteers
1) Is the volunteer role distinct from that of staff?	Front-line role of receptionist 'guarding' life-death boundary not suitable for volunteers. Division of hospice spaces into back and front stage, with volunteers not belonging in some backstage areas.	Clinical boundary between staff and volunteers shown in the release of patient information. Volunteer role of 'host' contrasts with, but is complementary to, the clinical role of staff.	Volunteer role is focused on food practices whereas most staff have a clinically focused role. Overlap in tasks is with low-status staff. Medicalised food becomes part of staff role.	Not sufficiently distinct to prevent 'professional' volunteers being treated as 'matter out of place': care assistant volunteers as anomalies and complementary therapists as ambiguities.	Volunteers undertake the same tasks as staff except for counselling.
2) How does the relationship between staff and volunteers generate and sustain the role?	Not applicable.	Volunteers support staff in performing 'living'.	Contact only with low-status staff or staff they do not report to. Low status staff cover for them.	Staff position them as 'dangerous', hence 'matter out of place' strategies. Staff and volunteers undertake 'boundary work' to protect their statuses.	Staff position the volunteers as non-professionals.
3) How does the hospice as an institution construct the role?	Not applicable.	Hospice 'scripts' 'living' in patient leaflets which provides the context for the volunteer role.	The medical model of care excludes volunteers. Volunteers are isolated from staff through clinical, temporal, spatial and organisational boundaries.	The medical model of care excludes volunteers.	Hospice 'scripts' 'living' in patient leaflets which provides the context for the volunteer role.

4) How does the context of death and dying shape the role?	Hospice is a heterotopic space sequestering death and 'guarding' the life-death boundary. Volunteers are kept away from patients who have died.	Volunteer role support staff in patrolling the life-death boundary to ensure death doesn't intrude.	Volunteers have less and less contact with patients who are 'actively' dying, as shown through food practices, with no contact after death.	Volunteers are undertaking 'bodywork' on dying patients which is professionalised territory.	Death is for experts so 'sensitive' cases given to experienced volunteers. Sensitive defined as closer to death.
Boundaries	Life-death boundary Staff-volunteer boundary	Staff-volunteer boundary Clinical boundary Life-death boundary	Staff-volunteer boundary Clinical boundary Life-death boundary Temporal boundary	Staff-volunteer boundary Life-death boundary	Staff-volunteer boundary Life-death boundary